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The development of a theory of psychological adjustment to multiple sclerosis based on accounts of subjective experience

JONATHAN REED BSc HONS

submitted in partial fulfilment of the requirements for the degree of
DOCTORATE OF CLINICAL PSYCHOLOGY

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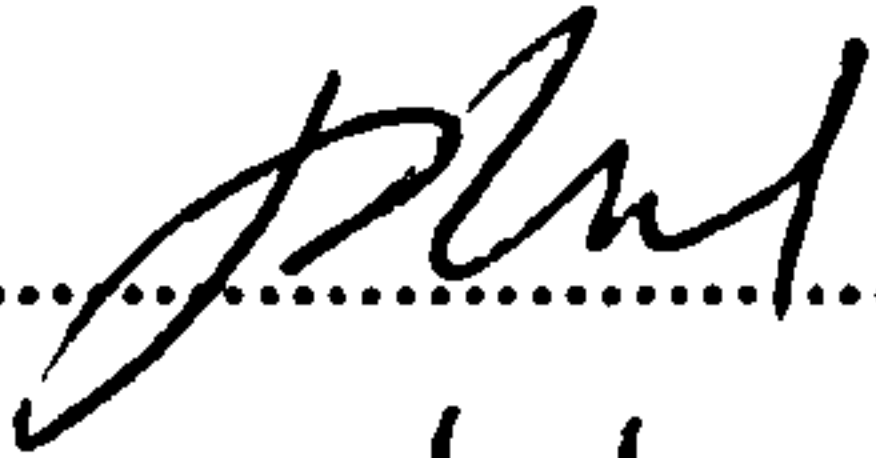
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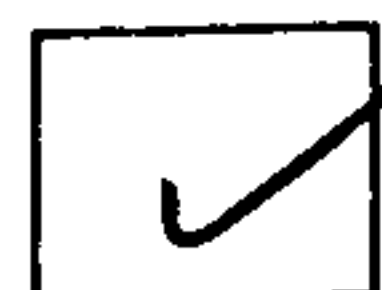
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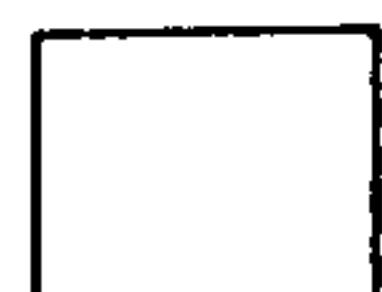
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ABSTRACT

This study explores the process of psychological adjustment to multiple sclerosis.

Fourteen participants who were given a definite diagnosis of multiple sclerosis between five and forty years prior to the study and who experienced the relapse-remitting form of the disease were interviewed face to face using a semi structured interview schedule. Grounded theory was used to analyse the interviews and to build a theoretical account of the process of psychological adjustment to multiple sclerosis.

The results suggest a model of adjustment in which some individuals with multiple sclerosis move from a stance of denial to a position of acknowledgement in response to the progress of the disease. Reaching acknowledgement allows individuals to adopt an active coping stance which can protect against negative psychological consequences. This adjustment process takes place against an overall process in which individuals experience multiple sclerosis as a progression through a series of different disease phases. Findings suggest that individuals also have to adjust within the social context. Role adjustment and communication were found to be central issues in the family adjustment process. Communication was also central to adjustment in the wider social context. Participants' service use suggests that they also undertake an adjustment from reliance on medical approaches to seeking out self help and alternative approaches. It is argued that this service use process reflects the individual adjustment process.

The findings are critically evaluated and compared to existing models of adaptation to chronic illness. The clinical and service implications are discussed. A critical discussion of the methodology is presented and implications for further research are explored.

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1.0 INTRODUCTION

Multiple sclerosis is a mysterious disease. Despite over a hundred years of research it is not known what causes it, the prognosis is uncertain, there is no cure (McDonald, 1983), there is a lack of clear understanding of the psychological processes involved in living with the disease (Vander Plate, 1984) and there is a lack of understanding about what service provision is available in this country (Thompson, 1996). Although there is little scientific understanding, the disease presently affects 2.5 million people world-wide and around 900,000 in the UK (Thomas, 1995). Onset is usually in early adulthood and individuals and their families have to learn to live with the disease for most of their adult life. Therefore there is a great need to develop understanding of the psychological processes involved in living with MS*.

In this introduction a brief overview of what is medically known about MS will be presented. This is followed by a review of the research literature examining the psychological aspects of MS. Research in this area was initially dominated by quantitative methods looking for simple cause and effects including a search for a psychological cause of MS and later the search for a common emotional reaction to the disease. Psychological research then began to focus specifically on the process of adaptation to MS, a concept that will also be reviewed here. More recently, qualitative paradigms have been used to look in more detail at the adjustment process. This research is an attempt to develop the qualitative stance in this area and to move away from the medical model surrounding psychology and MS. Arguments will be provided at the end of this introduction with relation to the chosen methodology.

* Multiple Sclerosis will be referred to by the common abbreviation MS throughout the text.

1.1. The disease process in MS

MS is a neurological disease in which the myelin sheath (the protective coating of the nerve fibres) is damaged. Initially, there appears to be inflammation of the myelin sheath, then once the inflammation subsides damaged is caused through a loss of myelin (demyelination) and patches of sclerosis (scarring or hardening) forming where the myelin once was. This damage results in interference of the electric signal through the nerve cell and either scrambles the signal or prevents signals getting through to different areas (Thomas, 1995). As different neurones are affected different symptoms occur. These can include numbness; paralysis; spasticity; fatigue; vertigo; problems in bladder control; sexual dysfunction; difficulty in communication; cognitive deterioration and visual impairments (Robinson, 1988).

The rate of progression of the disease is unpredictable. Although there are no medical signs at the time of diagnosis, people can be classified retrospectively into four approximate categories in terms of MS progression (Thomas, 1995). Around 20 per cent have a **benign** form of the disease where disability is minimal even after many years. Around 10 per cent of the population exhibit slow but steady deterioration without relapse or remissions called **chronic progressive**. Another 10 per cent experience a **rapidly deteriorating** form of the disease which can be fatal after 5-10 years. The remaining 60 per cent suffer from **relapse-remitting** form of the disease where symptoms come and go in the form of attacks which can affect any part of the body. Individuals often recover from such attacks but there is a gradual deterioration over time.

It seems essential to understand the psychological process of adaptation for a number of reasons:

1. The uncertainty of progress of the disease at the time of diagnosis.
2. The potential for incapacitating and possibly even fatal symptoms.
- 3 The potential to have long periods without any visible sign of the disease.
- 4 The often early onset in adulthood.

Review of the literature examining psychological aspects of multiple sclerosis

The body of research into the psychological aspects of MS can be seen from a historical developmental perspective as researchers have moved from one approach to another. Research paradigms have shifted from a quantitative view looking for cause and effect models using correlational and cross sectional designs based on medical ideas of pathology to more recent qualitative approaches based on subjective accounts of experience. This highlights the importance of understanding the context within which the research takes place and the assumptions behind the research aims.

1.2. The search for a common personality profile associated with MS

Research dating back to the 1870's onwards has tried unsuccessfully to find a cause for MS (McDonald, 1983) including early psychological studies. Inman (1948) examined a number of case studies and concluded that MS was a somatic reaction to intolerable mental conflict. Philippopoulos, Wittkower and Cousineau (1958) examined 40 patients with MS and 40 controls (nurses and other non neurological patients). Using case histories, tests of intelligence and projective testing, they found that the MS patients more often experienced unhappy childhood and rejection by parents, emotional

and psychosexual immaturity and morbid anxiety. They did not find any uniform premorbid personality but concluded that emotional disturbance may precipitate the onset and exacerbation of the disease. These early studies have been criticised for using measures that lack validity and reliability and for dubious conclusions about causality (Vander Plate, 1984).

Rather than looking for causal personality traits, other researchers looked instead for a common personality resulting from the MS. Harrower and Kraus (1951) examined 140 MS patients according to symptom severity using projective personality methods. They found those with more severe symptoms had higher personality constriction, dependency and a lack of somatic concern. In contrast the MS patients in remission had expanded personality and capacity for richer psychological experience. They concluded that the conditions imposed by the MS resulted in the changes. Again this study has been criticised for using projective tests with little consideration to reliability and validity (Vander Plate, 1984). Also the study used a cross sectional design which limits the extent to which it can be concluded that either personality causes or is a result of MS.

Overall evidence for a common MS personality pattern is therefore weak. Research paradigms have looked for simple cause and effect answers based on an assumption that there must be a pathological psychological as well as a physiological basis to the disease.

1.3 The search for a common emotional reaction to MS

Research paradigms then moved onto searching for common emotional reactions to the disease (Vander Plate, 1984). Antonak and Livneh (1995) in a review of the research into MS suggest that reported reactions to MS include aggressiveness, anger, apprehension, anxiety, denial, dependency, depression, euphoria, helplessness, hopelessness, hostility, invalidism, irritability, low drive, resignation and shock (Baldwin, 1952; Baretz and Stevenson, 1981; Philippopoulos, Wittkower & Cousineau, 1958; Surridge, 1969; Dalos, Rabins, Brooks & O'Donnell, 1983; Schiffer, Rudick & Herndon, 1983). This initially suggests that it is unlikely that there is one particular emotional reaction to the disease, instead there is likely to be a great variation of individual reactions. Researchers have, however, examined the role of depression as a common emotional reaction. There are a number of conflicting findings in this area.

Whitlock and Siskind (1980) compared 30 people with MS with 30 people with other neurological disorders. They found that MS patients were significantly more likely to be depressed using a standardised depression measure. An analysis of the antecedents to the depression, combined with the fact that some had depression shortly before the symptoms, led the researchers to conclude that in many cases the depression in MS is caused by nervous system damage. However, an alternative view could be that depression before the onset of MS could be due to other life events or to the worrying period where there can be a number of unexplained symptoms prior to diagnosis. Using a retrospective cross sectional design cannot not provide conclusive evidence about causation.

In contrast, Surridge (1969), using psychiatric case histories, compared 108 patients with MS with 39 patients with muscular dystrophy and found no significant differences in terms of depression. One-quarter of the patients with MS were thought to be depressed. Surridge concluded that in most cases the depression was clearly a reaction to the disease rather than to nervous system damage. Again this study makes strong claims about causality using a cross sectional retrospective design based on case histories.

In a more comprehensive study of emotional reactions to MS, Peyser, Edwards and Poser (1980) showed that the relationship between depression and MS was more complex. They examined psychological response as a function of a number of individual and disease related factors. They used the Minnesota Multiphasic Personality Inventory (MMPI) with 55 people diagnosed as having MS. Cluster analysis was used to determine if groups of individuals could be identified on the basis of the similarities of their responses to a number of variables. These included age, sex, length of disease, age at diagnosis, measures of physical and cognitive ability and the raw scores from the MMPI. Cluster analysis revealed six different groups which are summarised in table 1. The most psychologically distressed were cluster one (high physical disability; low cognitive ability) who had had MS for a long period of time and cluster six (low disability, high cognitive ability) who were recently diagnosed male participants.

Table 1 Summary of cluster profiles for participants in Peyser et al (1980) study.

	Cluster 1	Cluster 2	Cluster 3	Cluster 4	Cluster 5	Cluster 6
No of participants	8	13	13	10	3	5
Sex M/F	4 M 4 F	6 M 7 F	2 M 11 F	2 M 8 F	1 M 2 F	5 M 0 F
Age (mean)	45	31	49	41	38	31
Diagnosed (mean yrs)	18	5	11	11	7	4
Cognitive ability (Halstead Category Test. Halstead, 1947)	Low	High	High	Low	High	High
Disability level (Kurtzke DS; Kurtzke, 1965))	High	Low	Moderate	High	Low	Low
Psychological profile (MMPI)	High on most scales	High on denial	High on depression/ anxiety	Normal adjustment	High on Hysteria	High on most scales

This study suggests that psychological distress is likely to be different at different times and with different groups of people. However it is difficult to draw any firm conclusions from the study as the number of people in each cluster were very small. Also the MMPI may not be a good measure of emotional reactions to the disease and the researchers point out that none of the individuals had clinically significant scale scores.

Summary

There does not appear to be a convincing case for either a common personality pattern or set of emotional reactions to MS. Depression has been examined most often in terms of MS progression. However, it seems that incidence varies depending on the stage at which it is measured in terms of MS progression and which sub population of the MS population is assessed. Most of the studies examining emotional reactions are cross sectional measuring reactions at a particular point in time. For a disease that people may have to live with for 30 or 40 years the results may have limited applicability over time.

Early research into the psychological effects of MS also demonstrates that all research takes place within a certain context and with certain assumptions behind it. A major assumption in terms of MS seems to have been that individuals with MS have some sort of pathological psychological reaction or personality. This assumption may have been due to the dominance of the medical model searching for a (mental) illness process which can then be treated. Individuals with MS are placed in a powerless position in these early studies, with their viewpoint not being sought. Instead, research tried to quantifying individual responses to MS into discrete categories. The limited results suggest that the psychological impact of MS is more complex.

1.4 A review of the literature examining the psychological adjustment to MS

Following the search for common personality profiles and common emotional reactions, research moved onto examining psychological adjustment to MS. The

assumption here became less pathologising, that is people with MS are just normal individuals having to adjust to a particular disease (Vander Plate, 1984).

1.4.1 The theoretical concept of adjustment

There is little agreement regarding the concept of adjustment to chronic illness and disability (Antonak and Livneh, 1995) and research into adaptation often fails to examine the theoretical concept of adjustment. There are a number of broad theoretical viewpoints including behavioural, psychodynamic and cognitive approaches. It seems likely that adjustment will involve an interplay of these factors.

From a behaviourist stance adjustment involves the person's physical behaviour rather than what she or he feels (Russell, 1981). Adjustment involves finding new reinforcers and behaviours over time. Adjustment occurs when the person establishes new rewards and returns to a premorbid level of functioning (Fordyce, 1971).

Others define adjustment in psychodynamic terms as a process similar to bereavement (Matson and Brooks, 1977). In this approach emphasis is placed on the emotional reactions to the losses incurred in chronic illness and disability. Models using this theoretical approach often conceptualise adjustment as a series of stages, for example shock, denial, anger, depression, acknowledgement and final adjustment (Antonak and Livneh, 1995).

Another approach takes a cognitive view of adjustment in which adjustment is seen as an interaction between a cognitive appraisal of the situation produced by the disability,

the adaptive tasks required by disability and the coping skills the individuals possess (Moos and Tsu, 1977).

As well as examining adjustment to chronic illness and disability as a process, many researchers concentrate on adjustment as an outcome measure. Antonak and Livneh (1995) define adjustment in terms of psychological and social outcome. In terms of psychology, they view adjustment as a process which culminates in greater personal openness to experiences, improved self esteem, heightened self awareness and general acceptance and successful coping with the disability or illness. In terms of social adjustment, the process reflects movement from social withdrawal to collaboration with others. However, what constitutes an optimal psychological adjustment reflects personal values (Russell, 1981) and can be thought of as a culturally relative concept (Lazarus, 1961).

1.4.2 Studies of adjustment to MS as a discrete outcome

A number of studies conceptualise adjustment to MS as a discrete outcome measure.

Zeldow and Pavlou (1984) conceptualised adaptation to MS as a number of constructs including social poise, well being, autonomy, concern for others, reliance on others, lack of confidence and social contact as measured by the Interpersonal Dependency Inventory (Hirschfeld, Klerman & Gough, 1977) and the California Psychological Inventory (Gough, 1969). They found that physical health status and life stress predicted most of the variance on psychosocial adjustment in a cross sectional study

with a sample of 81 participants with MS. Greater physical disability was associated with lower adjustment whereas duration of illness had little effect.

Larsen (1990) conceptualised adjustment to MS using The Psychological Adjustment to Illness Scale (PAIS; Derogatis, 1986) which covers vocational environment, domestic environment, sexual relations, extended family relations, social environment and psychological distress. She found that duration of illness did not significantly influence psychological adjustment in a cross sectional study with 137 participants. The only significant differences were that individuals in remission had a lower psychological adjustment score than those not in remission.

Wassem (1992a) conceptualised adjustment in terms of the Bell Disability Scale of Adjustment (Bell, 1967) which measured attitudes and behaviour associated with adjustment to physical disability. She found that self efficacy (measure by the Self Efficacy for Adjustment Behaviours Scale; Wassem, 1992b) accounted for 24 percent of the variance in adjustment to MS in a cross sectional study with a sample of 62 participants. She also found severity of disability accounted for 35 percent of the variance.

Such studies seem to show that there is a diverse view on what can be viewed as 'adjustment'. One consistent finding seems to be that individuals with greater disability score less well in terms of adaptation to MS, but that duration of illness has little effect. All the studies were cross sectional and do not explain the process of adjustment over time.

1.4.3 Adjustment to MS as a process

Other studies have conceptualised adjustment to MS as a process. Matson and Brooks (1977) conceptualised adjustment as changes in self concept (the image one holds in one's 'mind's eye' of oneself) and proposed a model of the process of adjustment. They compared a group diagnosed with MS (n=174) with a control group (n=29) (population not specified) and found there was no significant difference in self concept scores between the groups. They then analysed the self concept scores of the people with MS and found that individuals with longer duration of disease since diagnosis had a higher self concept score. On psychological and emotional variables, there was a steady linear progression in self concept over time. However, while self concept increased over time post diagnosis, it was found to be mediated by the degree of impairment.

From findings and comments from patients the authors proposed a model of adjustment based on Kubler Ross's (1969) adjustment to death. They felt that adjustment proceeds through four stages.

Stage 1 Denial

This is where patients act with disbelief and an unwillingness to accept the diagnosis. In this stage symptoms are concealed and help from others refused. Individuals hold onto past values in an attempt to continue past activities despite impaired functioning.

Stage 2 Resistance

This involves finding information about the disease and searching for a cure. The predominant attitude is one of 'it won't get me down'. Individuals attempt to gain some control over the disease. At this stage individuals start to accept some help from others. There are initial signs of recognition of the need to change one's life orientation.

Stage 3 Affirmation

This is a time of self confrontation as the person realises that life's priorities must be rearranged because of their illness. Grieving may occur for the loss of the individual's former active and independent self. Individuals may start to become public about their new MS identity and start to learn to accept help from others without devaluing him/her self.

Stage 4 Integration

The final stage is characterised by attitudes such as 'I know it's part of my life but I don't think about it much'. Individuals are able to cope with the disease without tremendous emotion and distress which allows them to expend energy on other aspects of living. When individuals reach this stage they are able to have more intimate relations with others.

The model has been criticised because it is based only on the scores from the self concept scores and comments from participants and has not been empirically tested.

It also only provides a broad outline without revealing the exact psycho-social process of people who incorporate chronic illness into their everyday life (Matson and Brooks, 1987).

1.5 Studies examining individual accounts of the process of adaptation to MS

More recent studies have moved away from research paradigms aimed at quantifying the psychological experience of MS into paradigms examining subjective accounts of MS in more detail.

Conrad (1987) suggests that there are two ways of studying the illness experience. Firstly there is the 'outsiders' perspective which attempts to minimise or ignore the subjective reality of the person. The patient, illness or disease is seen as an object to study. This approach mainly takes a deductive approach i.e. testing hypotheses. In contrast the 'Insiders' perspective focuses directly and explicitly on the subjective experience of living with and in spite of illness. This follows a more inductive approach taking personal accounts from the perspective of people with illness.

Matson and Brooks (1987) state the job of managing chronic illness (which they define as an active mode in which people apply specific measures in the attempt to deal with perceived illness concerns) is mainly the individual's responsibility and not the job of clinical professionals. Therefore analyses which delve further into the details of the personal efforts to handle and interpret chronic illness speak directly to the essence of chronic illness. They interviewed, using a semi structured interview, nineteen people with MS with different levels of disability and duration since diagnosis. Transcripts

were analysed using a grounded theory type method (Glaser and Strauss, 1967). Data was categorised into themes. From this analysis three main categories emerged:

1) Adjustment at individual level

The first category was the individual physical/medical level in which there is a shift from the expectations of acute illness to a chronic illness pattern. Themes at this level include individuals having to learn to manage symptoms and to learn to distinguish the significance of physical changes and perhaps to predict and control them. The impact of the doctor-patient relationship changes as patients gain more experience with their illness. Also information gathering becomes important to MS patients and they tend to find printed material or suggestions from others with MS more useful than medical consultations.

2) Adjustment at the social level

As well as at the individual level, themes also emerged about the social dimension. They suggest that the family unit also attempts to manage the illness process. Patients have to negotiate with friends in an attempt to find a mutually satisfactory basis for continuing the association. Work relationships and patterns change and need to be negotiated. Stigma becomes an issue with faulty social performances leading to embarrassment. Also social isolation occurs with the narrowing of social contact because of both physical limitations and also the expenditure of effort.

3) Adjustment as a social-psychological task.

A final general category is the active social-psychological management which includes subjective adaptation. They suggest accepting the illness distinguishes managing from explorations or denials of chronic illness role. This includes the realisation that physical selves had become quite different and there is a shift so that symptoms and their consequences become part of themselves and are no longer ignored or explained away. Self-redefinition occurs as there is shift in one's view of self as person who has MS to include a perception of oneself as an active manager of the illness. Self concept, however, remains fluid and is still responsive to doubts and social trials. They conclude that how individuals incorporate the active, managing self with symptoms, decreased functioning, high uncertainty and possible disease progression becomes a challenging social psychological task.

Matson and Brooks' (1987) account highlights the importance of individual, social, and service elements in the process of adjustment and any adequate account of adjustment to MS needs to incorporate these. It also highlights the complexity of adjustment to MS that is revealed when personal accounts are used. However, the account is limited in that it does not examine process in a temporal way. It suggests a number of factors involved in the process but does not examine the process itself. Also it does not account for the heterogeneous nature of the MS population. MS is a complex disease with a variety of symptoms. Matson and Brooks' account tends to treat MS as a single entity.

1.5.1 Adjustment as a narrative reconstruction

Another study which also examines subjective accounts highlights the way in which accounts are constructed. Robinson (1990) used a narrative analysis technique to show the way in which accounts of MS are constructed to present a particular view. He asked individuals with MS to write their life stories including anything in their lives (events, experiences or feelings) which were important to them. A random sample of 50 accounts were selected from 450 submitted accounts.

Robinson used Gergen and Gergen's (1986) framework for the narrative analysis which suggests that all narratives fall into certain patterns. These are firstly **stable narratives** in which life is explained as a series of events or experiences located in literal rather than personal time. Secondly there are **progressive personal narratives** into which there is a positive construction of events and experiences in terms of personal goals such as occupational careers or personal relationships. Some of these narratives are very dramatic and evoke heroism and courage. The final pattern are **regressive narratives** which present stories of continual and increasing discrepancy between valued goals and the possibility of their attainment. These include tragedies and sad narratives.

Robinson found that 20 % were stable narratives, 52% were positive narratives, 10% were regressive narratives and 18% could not be allocated. He suggests that moulding personal accounts into progressive narratives allows a sense of group, as well as

personal, control over the biomedical trajectory of the disease. The main limitation of the study is that it does not explore the sequential process of constructing accounts.

Do individuals construct positive narratives from the diagnosis period? Or do they start to construct such narratives after many years of living with the disease?

1.6 A review of the literature examining service approaches to MS

Chronic neurological illness such as MS presents challenges for healthcare services.

The current system is designed to deal with emergencies and acute care, is orientated towards symptoms and external causes, and teaches short-term self maintenance coping strategies (Earll, 1995). This pattern of service delivery can sometimes be unhelpful for individuals with chronic neurological illness. For instance, Newrick and Langton Hewer (1984) found 32 out of 42 patients with Motor Neurones Disease disliked attending neurological outpatient clinics. They listed reasons including the wait for transport, the discomfort of the journey, seeing ever changing junior medical staff, lack of access to information and doctors ignorance about the disease and control of symptoms.

There is no research examining the available services for people with MS in the UK (Thompson, 1996). There is some agreement that adequate services need to be interdisciplinary. The working party report of the British Society of Rehabilitation Medicine (1987) states the need for community disability or rehabilitation teams.

There are also few models of psychology services for people with MS. Thompson (1996) describes the role of psychology within a specialist rehabilitation unit in the UK.

The psychologist role as part of a multi disciplinary team included goal planning, stress management and cognitive rehabilitation. In the US, Pavlou, Johnson, Davis and Lefebvre (1979) describe a group treatment programme specifically for adjustment. In this programme individuals with MS are given information and tips about coping and Psychologists help in the process of labelling and understanding feelings. The approach highlights the message that although there is little control over disease there is some control over how individuals can interpret it. Patients talk to others and 'learn the ropes' about how to cope with MS.

1.7 Summary of the research literature examining psychological aspects of MS

This introduction has shown that early research into psychological aspects of MS concentrated on searching for common personality patterns and emotional reactions to the disease. The evidence for such patterns is not convincing and the research tends to show that emotional reactions to MS differ depending at what point reactions are measured and which individuals are being assessed. Research then developed to look at psychological adjustment to MS. There seems to be little consensus about what the construct of adjustment to MS means. Many studies take the concept of adjustment to be a desired outcome on a number of psychological variables. This carries the assumption that the researcher knows a priori what constitutes a good adjustment to MS with little reflection about the position those with MS have in relation to the person undertaking the research. Participants have no real voice. Research has recently begun to examine subjective accounts of individuals with MS, examining how such accounts are constructed and looking in more detail at the process of adjustment. These ideas form the background to the present study.

1.8 Research aims

The present research will be based on personal accounts of MS and look in more detail at the process of adjustment. No studies have been undertaken in the UK using an inductive grounded theory approach to examine the process of adjustment. This is important as there are different service structures and different cultural considerations compared to a US population.

In addition previous accounts of the process of psychological adaptation have treated the MS population as a homogeneous group. As was stated in the introduction there are at least four distinct patterns of progression of MS (Thomas, 1995) and this is likely to have an effect on adjustment. Also there are no accounts looking in detail at temporal progression of individual and social adjustment associated with the progression of MS and the progression of healthcare service use.

For these reasons more detailed theoretical accounts of the adjustment to MS are required. Grounded theory is about theory development and therefore hypothesis testing is not appropriate. Instead this research is based on a number of research aims.

- 1 To construct a theoretical account of the process of adjusting to multiple sclerosis based on individual personal accounts.
- 2 To include in this account details of the individual and social adjustment process.
- 3 To develop an account of the way that service use fits into the adjustment process.

1.9 Reasons for using a qualitative approach in this study

Bryman (1988) suggests that there can be both technical and epistemological reasons for using qualitative research methods. In this study qualitative methods were used for both these reasons.

1.9.1 Technical reasons for using qualitative methods

Qualitative methods were considered the most appropriate for the research aims.

Firstly the research involved in depth interviews about the subjective experience of living with MS which necessarily results in a large amount of unstructured data. The grounded theory method was thought to be a good way of analysing this data.

Secondly one of the aims of the research was to generate a theoretical account of the process of psychological adjustment to MS and grounded theory provided a method for developing theory inductively. Thirdly previous research suggested that adjustment to MS may be a complex process. Qualitative methods were thought to be appropriate in addressing this as they tend to seek to describe and explain whole, complex events occurring in real life contexts (Orford, 1995).

1.9.2 Epistemological reasons for using qualitative methods

As well as the technical reasons there were also epistemological reasons for choosing qualitative methods. Quantitative methods tend to be associated with a positivistic stance towards studying psychological phenomena. This involves seeking to establish objective knowledge of universal laws of cause and effect through the testing of

specific hypotheses against phenomena in the empirical world (Henwood and Pidgeon, 1995). The assumption behind such a position is that there is an objective world waiting to be discovered. Qualitative methods on the other hand allow the use of a social constructionist stance which views knowledge as being generated within networks of social activities and systems of socially constituted meanings. The assumption here is that there are different ways (constructions) in which the world can be explained. Sherrard (1997) argues that this particularly applies to social situations (for example, perception of social characteristics) as against physical perceptions (for example sensory observations).

In terms of this study, the use of a social constructionist stance will hopefully allow the viewpoints of individuals with MS to be seen as valid in their own right. This was thought to be particularly important as the majority of individuals with MS experience the disease without expert help and interpretation. Also in the past researchers examining the psychological aspects of MS have rarely sought the views of individuals with the disease.

Another benefit of taking a social constructionist stance is that it allows greater flexibility in exploring the role of myself as a researcher in constructing the research account. This includes being open about the reasons for choosing this research and approach, being clear about my assumptions behind the research, being clear about the interpretative processes that are taken in the course of the research and exploring my social and cultural position in relation to the participants and the way that they position me (Salmon, 1996). It has been argued that being clearer about these subjective

processes results in a more valid approach than accounts which obscure such processes (Harding, 1991). Also it has been recently argued that the way research reflexivity is addressed may be useful as an overarching criterion for good research across different approaches (Stevenson and Cooper, 1997).

1.10 Evaluation in Qualitative Research

The standard ways of evaluating quantitative methods are through the concepts of reliability (which assesses the consistency of observations) and validity (which is the generalised truth of statements). These concepts are problematic for qualitative methods because no claim is being made for a single universal account of the social world. There is, however, still the need to evaluate qualitative methods and several concepts have been proposed for this task. In order to evaluate the study the following concepts were used:

Auditability (Sandelowski, 1986)

This allows the steps and decisions taken by the researcher to be followed by those reading the research. It is different from the traditional notion of reliability for quantitative research, where the implication is that any researcher undertaking the steps will come to the same conclusion. For this study other readers may not share the author's interpretations because they may have different assumptions and may be positioned differently in the interviews by the participants (for example a medical doctor may not have produced the same material from participants as a clinical psychologist). However, readers should be able to follow how the analysis was carried out. In this study this was addressed in two ways. Firstly the method section attempts

to clarify, with examples, how the process of analysis of the interviews was carried out. Secondly a research diary (Appendix 1) was kept to highlight the steps taken and the decisions made by the researcher throughout the research process.

Respondent Validation (Silverman, 1993).

This concept allows validity to be tested in relation to the specific concerns of the individuals in the study rather than as a more universal psychological truth.

Respondent validation involves the degree to which participants recognise and agree with the findings from the research. This was addressed in this study by sending participants a copy of the initial analysis for their feedback and comments.

Rhetorical Power (Henwood and Pidgeon, 1995)

This concept examines how persuasive the arguments in the research are to others.

This was addressed by sending a copy of the results to a clinical psychologist not connected to the study or to the local services but working with people with MS. Also a copy of the findings was sent to the welfare officer of the Multiple Sclerosis Society for feedback and comments.

Reflexivity (Stevenson and Cooper, 1997)

This concept is about the extent to which the researcher reflects on the process of his or her research. This was addressed through the process account in the researcher's diary and in the discussion where the role of the researcher in constructing research will be explored.

2.0 METHOD

2.1 Design

A qualitative study of subjective experiences of multiple sclerosis, using grounded theory (Glaser and Strauss, 1967).

2.2 Participants

2.2.1 Recruitment

Fourteen participants took part in the study. Two participants were recruited through the caseload of the consultant Neurologist. He was given twenty information sheets (Appendix 2) and contact forms (Appendix 3) which were handed out by him during outpatient clinics, to patients with multiple sclerosis, but with no significant cognitive impairment.

Twelve participants were recruited through a local branch of the Multiple Sclerosis Society. The branch welfare officer was given thirteen information sheets and contact forms. She contacted participants by phone and sent them the materials by post. Again she was asked to omit individuals with significant cognitive impairment.

Once the participants had been given the information sheet and contact form they were required to send the contact form back to the researcher indicating that they were willing to participate in the study.

In this study the recruitment of participants and analysis of interviews can be divided into three phases. These were phase one the initial sample; phase two further sampling to extend the emerging theory; and phase three negative case analysis to challenge the emerging theoretical account. This allowed the data collection and analysis to occur simultaneously which is a critical feature of grounded theory (Pidgeon, 1996a).

2.2.2 Participant characteristics

Table 2 Summary of participant characteristics.

Participant name*	Gender	Age	Time since diagnosis (years)	Walking Aid	Marital status	Children	Employ-ment
Mary	F	57	13	Wheelchair	Married	2	N
Keith	M	59	15	W/stick	Divorced	2	N
Ian	M	60	10	W/stick	Single	-	N
John	M	64	20	W/stick	Married	1	N
Kathy	F	43	7	Wheelchair	Married	2	N
Susan	F	55	12	Wheelchair	Divorced	2	N
Bill	M	54	9	Wheelchair	Married	2	N
Peter	M	58	10	Wheelchair	Married	1	N
Irene	F	66	20	Wheelchair	Married	-	N
Vera	F	78	45	W/stick	Widow	2	N
Julie	F	37	12	Wheelchair	Divorced	3	N
Charles	M	55	10	W/sick	Separated	2	N
Pam	F	51	15	Wheelchair	Married	2	N
Barbara	F	63	12	W/stick	Married	1	N
Total	8 F 6 M			8 W/chair 6 W/stick	8 M 3 D 1 S 1 W	12 with children	None
Mean		57	15				
Median		57.5	12				
Range		37-78	7-45				

The details of participant characteristics are summarised in table 2. The order in which participants were recruited is summarised below along with a biographical sketch of a representative participant from each phase of the research (1*: 2*).

Phase 1

A sample of five participants was used for the initial analysis. This included two people from the neurologist's caseload and three members from the Multiple Sclerosis Society. All participants at this phase had a relapse remitting type of MS.

Mary aged 57 had been diagnosed with MS for 13 years. Before being diagnosed she had worked as a personal assistant. Her MS had developed through periods of relapse and remission but she had not had a relapse for two years prior to the interview. She found it difficult to walk and used a wheelchair or a stick when going out. She also found she became tired very easily. She was married and had two grown up children.

Phase 2

In the second phase a further five participants from the Multiple Sclerosis Society were recruited in order to extend the emerging theoretical account. Participants at this stage included individuals with greater disability and different patterns of MS progression. Two participants at this stage had relapse remitting MS, two had progressive MS and one had the benign form of MS.

1* All names and immediate identifying information have been changed.

2* Due to lack of space biographical accounts of the other participants are recorded in Appendix 18

Bill was 54 and had been diagnosed with MS for nine years. He used to work as a lorry driver but had had to give up work very soon after diagnosis. His MS had progressed rapidly with no remission and he was significantly disabled at the time of the interview. He could not use his arms or legs and his voice was becoming weaker. He had an electric wheelchair which he used both indoors and outdoors. He was married and had two children through a previous marriage.

Phase three

Four more participants were recruited from the Multiple Sclerosis Society for the third phase. This involved theoretical sampling in which negative case analysis was undertaken in order to challenge the emerging theoretical account. All four had relapse remitting MS.

Julie aged 37 was diagnosed with MS 12 years ago. Her MS had not affected her much physically until a year ago when she suddenly lost the use of her legs. She had suffered in the past from severe mental health problems and alcohol problems and had been in hospital several times. She was divorced and her three young children were looked after by somebody else. She lived with a friend who acted as her carer and lived in a flat with many stairs which meant she could not get out much. She was waiting for the local authority to rehouse her.

2.3 Development of the interview schedule

The interview schedule (Appendix 6) was devised primarily as an aid to encourage people to talk about their experiences of living with MS and to ensure that certain main areas of experience were covered. It was not standardised or administered in a standardised way. This was to firstly to encourage individuals to talk in a honest and open way which meant being non directive to allow participants the initiative.

Secondly since grounded theory is based on data rather than from testing a priori hypotheses there was a need to ensure that the data was not over structured by predetermined questions. Instead it was important to follow participants' concerns.

The schedule was divided into six sections broadly following a temporal format:

A Initial information.

This covered information about personal circumstances such as age, domestic situation, etc.

B Experience prior to diagnosis

This covered information such as the individual's first recognition of symptoms, their meaning at the time and the decision to seek medical help.

C Diagnosis

This covered how the diagnosis was communicated, how much information was given and how long it took for news to sink in.

D Progress since.

This covered how the disease had progressed, how individuals had coped, feelings associated with different experiences and the role of other people throughout.

E Role of services.

This covered positive and negative experiences of health, social and voluntary services, and views on service development.

F Ending

This section contained two questions that were given to every participant as a way of bringing the interview to a closure. These asked what participants felt they had learnt from their experience of having MS and whether they had anything thing else that they wanted to cover.

Copies of the initial schedule were prepared in consultation with my research supervisor, a clinical psychologist not connected with the study but working with people with MS, and representatives from the local MS society. The questionnaire was also scrutinised by the ethics committee which approved the research.

A second interview schedule was designed for the purposes of negative case analysis (Appendix 12).

2.4 Procedure

2.4.1 Ethical considerations

Ethical approval was sought and given by the ethics committee connected to the NHS Trust employing the consultant neurologist (Appendix 7). The research was also scrutinised by the committee of the local branch of the Multiple Sclerosis Society (Appendix 5).

2.4.2 Recruitment procedure

The consultant neurologist (Appendix 4 for the letter explaining procedure) and the welfare secretary of the local MS society gave potential participants an information sheet detailing what the research was about, what would be expected of them and their right to withdraw from the study at any point. It also contained a contact sheet asking them to write their telephone number and address which was to be sent back to me if they were willing to participate. When the sheets were received participants were contacted by phone and an interview was arranged. Participants were offered a choice of interview in their own home or at a local office. All of them chose to be seen in their own homes.

At interview participants were asked to sign a consent form (Appendix 8) and reminded of their right to withdraw from the interview or turn off the tape recorder at any time. A standardised introduction written by the researcher was read out (Appendix 6) and participants were asked if they had any questions. The interviews lasted between forty five minutes to an hour and a half. Following the interview a standardised debriefing procedure occurred (Appendix 6). This included a brief summary of the purpose of the research, a check on whether it was alright to send transcripts of the interview and a summary copy of the findings to the participant once they were written. Participants were also asked how they were feeling after the interview and if there had been any parts of the interview that were particularly difficult. There was also a procedure in place in case anyone was feeling distressed

after the interview. This included 1 Checking how people were feeling. 2 Talking through any difficult issues immediately. 3 Giving a contact telephone number in case participants felt distressed after the interview. 4 contacting a local clinical psychologist if participants continued to feel distressed (Appendix 6).

Interviews in Phase One and Two were recorded on tape and later transcribed. In Phase Three interviews were recorded and the main points were transcribed from the tape. Participants in phases one and two were sent copies of the transcript and asked to verify that it was a correct representation of the interview.

2.4.3 Analysis of the interviews

Analysis was undertaken using the grounded theory methods devised by Glaser and Strauss (1967). The analysis took part in three phases.

Phase One

The first five interviews were analysed initially. Each interview was given a reference number and then each page and each line was numbered. This enabled each piece of text to be identified by a reference number (e.g. interview 2 page 5 line 12). The interviews were repeatedly read and each section that contained a central concept was coded (Appendix 9 for an example of a piece of text and the way it was coded).

Central concepts were derived by either summarising key pieces of text with a descriptive label or by interpreting key pieces of text with a theoretical label (Pidgeon, 1996a). Some parts of the text contained sections that could be coded into more than one concept. Concepts were recorded onto index card system (Appendix 11 for list of

initial concepts). Each card was headed with a category label (for example communication of diagnosis) and contained the reference numbers together with a brief summary of all the pieces of text coded according to that category label (Appendix 10 for an example of an index card).

Phase two

A similar process was used to analyse the next five interviews. The transcripts were numbered and repeatedly read. Sections of the text that corresponded with the initial concepts were identified along with new concepts in order to expand the emerging theoretical account.

Categories on the index cards were then further defined. Some categories were merged (for example communication of diagnosis and reaction to diagnosis were sorted into a broader theoretical category of diagnosis phase). Categories which did not relate to research aims were discarded. The categories were then sorted into clusters relating to a central theme (for example active ways of adjustment). These were further defined using examples from the interviews and were written up into a draft results section. The writing process enabled further definition and restructuring to occur.

Phase three

In this phase the main points were transcribed from the tapes of the final four interviews and coded in a similar process to the initial analysis. The concepts from

these interviews were then compared to the emerging theoretical account and differences and similarities were noted.

3.0 RESULTS

Research aim one: To construct a theoretical account of the process of adjusting to multiple sclerosis based on individual personal accounts.

Research aim two: To include in this account details of the individual and social adjustment process.

Overview

The analysis of the interviews resulted in a large number of theoretical and descriptive concepts. To address research aims one and two, the concepts were organised into five central themes which represent an attempt to define and explain the process of psychological adjustment to MS. Analysis of the interviews suggested that individuals experience MS as a series of different phases each providing different concerns and adjustment tasks (theme one). A broad adjustment process takes place across these different phases from a denial of MS at the pre-diagnosis period to an acknowledgement of MS (theme two). This acknowledgement allows an active adjustment stance (theme three) to take place. Individuals do not go through this process alone, they have to work out their adjustment within a social context (theme four). Finally the third research aim is addressed through analysis of participants' use of health, social and voluntary services and the way this use reflects the psychological adjustment process (theme five). The third phase of the study in which the analysis is evaluated by theoretical sampling is reported at the end of the results section.

3.1 Theme one: Individuals experience MS as a series of phases

This first theme reflects the point made in the introduction to this study that adjustment is a difficult concept to define. Rather than a single adjustment process to a unitary concept, participants experiences of MS were highly individual and continued over time. Analysis of the interviews suggested that individuals' experiences could be organised into a series of different phases.

a) The prediagnosis phase-the move from ignoring symptoms to seeking medical help

Most individuals in the study could trace their MS back to many years before diagnosis. They suffered in some cases up to 30 years of strange bodily sensations which were usually well outside the realm of ordinary experience. Individuals described their legs not responding to the will to move them, inexplicable falls, loss of bodily feeling, stumbling around and dropping things. Mary explained:

"I was out walking .. walking along the seafront and I thought I don't feel quite right here. I felt I was walking on cotton wool or rubber.. you know a bouncy sort of rubber.. I can't really explain but it was as if I was bouncing along." 1.5.7. *1 *2

For many these pre diagnosis sensations were transitory in nature and although not easy to explain did not at the time suggest a serious threat. Individuals tended to ignore or dismiss them or attributed them to some other cause. John summed up the attitude of many:

"It was just one of those things.. perhaps I had been working too hard." 4.4.6.

At some point however participants moved from being able to dismiss the sensations to realising that they may be more serious. This seemed to occur when the sensations

***1 Names and quotes have been disguised to preserve anonymity. Reference numbers refer to the interview number, page number and line number of the interview transcript.**

***2 Quotes have been selected that best illustrate descriptive and theoretical points.**

became more persistent or had a significant effect on the participant's life. Mary explains how this process occurred for her:

"I suppose when my husband realised that I was staggering around and had trouble getting up the stairs. I think he said to me, ' Don't you think you sort of better go and get it seen to?'" 1.6.14.

Overall these experiences suggested that a process of adjustment occurred from having strange bodily sensations to seeking medical advice in order to explain them. Different individuals went through this process in different time frames but eventually everybody in the study received a definite diagnosis of multiple sclerosis.

b) The diagnosis phase- The way the diagnosis is communicated and its meaning

From the interviews the experience of the diagnosis phase centred around two concepts. These were the way the diagnosis was communicated and the meaning of the diagnosis. These in turn influenced the way in which participants reacted to the diagnosis.

i) Communication of diagnosis.

The way the diagnosis was communicated appeared to have a significant impact.

Mary, Kathy and John were all told their diagnosis after other family members had been told. This resulted in family tension for some as the one family member had to keep the diagnosis secret sometimes for several weeks from the other. It also placed the individuals with MS in a powerless position with no access to information about what was happening to them. All three participants felt angry about this. Mary explained how this made her feel:

"I subsequently found that my husband had known what was wrong with me all the time. And I'll be honest I was furious. I felt for heavens sake it's my body.. why on earth couldn't anybody have told me what was wrong with me instead of leaving me all up in the sky and you know not having a clue what happened." 1.4.10 & 21.

Some participants found the way the diagnosis was communicated to them had a significant impact on their initial reaction. For instance Ian was told he had MS without any preparation and felt shocked:

"He (the consultant) just sat behind the desk and told me I'd got MS. ..And I'd only met him on the odd occasion in (Hospital name). Yes it was a very brutal way of doing it."
3.7.11.

He felt anxious afterwards every time he visited the hospital and felt that it had affected his relationship with doctors for years afterwards. However, other participants found that they preferred to be told straight out and the impact was less severe which showed that preference for the way the diagnosis was communicated differed on an individual basis.

ii) The meaning of MS

The other major factor influencing adjustment at diagnosis was the meaning that the diagnosis had for participants. Some participants had little idea of what MS was and therefore the impact was limited. Bill explained:

"He (GP) told me that I'd got MS.... well I'd never heard of it...it meant nothing to me."
7.3.8-9.

Comparison of the interviews revealed that a common meaning was the idea or image of a worse case scenario. This was a persistent anxiety provoking idea or image about what the worse case scenario was in MS. For many this tended to be an image or idea of MS as a rapid development into a wheelchair and dependence. For some this was present from the period of diagnosis or before. For others it was developed later and acted as a point to compare the progress of their own MS.

Some constructed this image from the media. Ian described his first thoughts on hearing his diagnosis:

"I mean the only person I'd ever associated with MS was Jacqueline Dupre` the cellist. And I mean she had the progressive disease and then you automatically think of a career gone and somebody in a wheelchair." 3.7.17-19

John developed a worse case scenario image of MS from his first visit to the MS society:

"But it was only when I went to the first branch meeting that I met other members there who were in a much worse condition than I was. They were in wheelchairs and couldn't walk. Then I began to realise that this might be a bit of a problem." 4.5 2-6

Participants who were already significantly disabled also seemed to have a feared worse case scenario. Bill who was very disabled talked about the worse case scenario in terms of loosing his voice and of MS as a fatal disease:

"There was a boy.. dead now with multiple sclerosis.. he couldn't talk.. couldn't hear a word he said.. Now young (Liz) another girl with MS .. she's got a weak voice.. before I could talk to her but now you can't understand what she says." 7.4.27.

Ian talked about the worse case scenario as loss of independence:

you can only imagine what it must be like to wait in bed and wait for somebody to come in and tell them to get up. ... But if you are so dependent it must be awful.. I suppose it is almost like going back to being a baby." 3.22.3.

This highlighted that the worse case scenario while often based on some real case example was also constructed and contained an element of a feared image or idea. Ian talked about 'one can only imagine what it must be like'. John was pulled towards the image of the most disabled people with MS. The image or idea also required that individuals developed a strategy from preventing it from becoming overwhelming.

John explained how he distanced himself from the worse case scenario:

"And I thought well if it progresses quickly I'll end up like that (very disabled). And when I found out a bit more and thought not necessarily so, there were other members who were in the same position as I was. And I discovered that they had had it quite a number of years and they were still like that so I thought it is not going to be so bad after all." 4.5.6.

Others used denial or avoidance as a strategy. John explained how he felt this worked:

Some people don't join the branch because they don't want to mix with people worse off than they are see... They ignore it and pretend it is not there.. 4.15.18.

c) The remission phase - MS fades into the background

The majority of participants had the type of MS that was characterised by cycles of relapse and remission. There was a great deal of individual variation in the pattern and length of these cycles. For some participants such as Keith and Vera their MS was in remission for years at a time after the diagnosis. They returned to normal everyday living and although the threat of MS was always there after some time it seemed to fade into the background. In these cases it was possible to return to a similar position to individuals in the pre diagnosis phase, that is they could deny the seriousness of their condition. Keith found that he did not have to acknowledge that he had MS for a long while after diagnosis:

"It took a while for the news to sink in because apart from my eyesight I didn't feel bad at all for years." 2.5.9.

Other people had relapse periods but also long phases of remission where again MS did not have to be acknowledged. Ian returned to work after the diagnosis and wanted to put the MS to the back of his mind:

"I think one is quite happy to be told what you've got but I think you, well I did, want to push it to one side." 3.14.23.

d) The relapse phase : leading to gradual deterioration.

Initially most people who had relapse periods found they acted as an interference in their everyday lives. Participants would take time off work or from everyday living and then when the relapse subsided they would return to normal. During this period the main concern seemed to be adjusting to a pattern of periods of health interspersed with periods of illness. However over time each relapse period causes some neurological damage which leads to gradual disability. The process then becomes one

of a gradual adjustment to the gradual onset of disability. This provides a pressure to acknowledge the effects of the disease but this was often resisted. Mary explained how she denied that this was happening to her:

“But I suppose I wasn’t prepared to admit that over that period I was getting gradually worse.” 3.8.17.

The process seemed to occur in many cases over a long time period of several years and it was not always possible to notice changes on a day to day basis. One way individuals realised that they were becoming more disabled was by using activities as markers. John summed this process up well:

“ To take the kitchen as a yardstick. A few years ago I thought that it would be quite nice to have beams on the ceiling and I put the whole lot up single handed. There is no way that I could do that now.. so there is tangible evidence that things have got worse.. but on a day to day basis it’s not noticeable.” 4.11.22.

Keith used activities as a marker for what he was still able to do:

“It’s like I belong to the Natwest down on the moor and I do find it an effort to get down there but so far I’ve managed to .. but when .. if.. the time comes when I can’t get down there .. I don’t know.” 2.16.14.

Therefore, for many participants, after the initial reaction to diagnosis and a period of adjusting to periods of illness it took several years before the MS started to affect them significantly. This allowed for a more gradual adjustment process.

e) Rapid changes: Experiences of crisis and loss

Although for many adjustment seemed in the main to be a gradual process there were times where individuals had to adjust to sudden changes. Participants found this occurred when their MS resulted in sudden changes in role or when important activities could no longer be undertaken. While it still took a period of time to adjust to these changes, the nature of the adjustment process seemed different. It was characterised by sudden loss which produced more of a shock reaction.

Ian found he had to suddenly adjust to not being able to work many years after he received his diagnosis. He summed up his reaction as a:

"culture shock.. suddenly not working any more..not having to go out and coming home." 3.15.23.

A similar process occurred for several people when they reached a sudden point where they had to give up driving. Mary explained:

"I was coming home one day with somebody .. I couldn't get my foot from the accelerator to the brake quickly enough and it frightened me so I just brought the car home and parked it and never got in it again." 1.18.11.

This had profound meaning for her:

"It's the loss of independence that I find difficult." 1.18.10.

Individuals with rapidly progressing MS also had to adjust to sudden changes. Bill explained this process:

"(after diagnosis) The doctor said well it's not critical.. you'll live with it'.. you will just go downhill gradually... Gradually!! .. cause I was walking and now I can't .. what you do today you can't do tomorrow...I was in the other flat and I just fell down... I couldn't get up and I had to crawl to the chair to get in the chair.. now this hand shakes so much I can't put anything up to my mouth and this hand is too weak to get to my mouth." 7.2.14.

This process was characterised by a regular and continuous loss of ability and changes in roles and activities. Bill, Susan and Kathy who all had this pattern had to develop a number of coping strategies to deal with this. These included denial, the use of humour, hope and an appreciation for what they still had especially in terms of relationships. None of them appeared to be in significant psychological distress.

9) The loss of mobility: MS becomes visible

The move to using a stick or a chair appeared to be a significant step that required additional adjustment for many participants. Using a walking aid meant that participants' MS, which had been a predominantly invisible disease, suddenly became visible. John explained how he was forced to adjust to using a stick:

"Because it took me ages before I started using a walking stick. That only came about because I got down town once and found I couldn't walk back unaided. As chance would have it I happened to be outside an ironmongers and they sold walking sticks. So much to my great reluctance I thought the only way that I can get home is to have an aid. So I went in and bought one and I have used one ever since." 4.14.13.

Part of the difficulty for participants was the perception of being disabled. Mary explained what being in a wheelchair meant to her:

"I see old ladies hunched over in their wheelchairs with their blankets and I think don't let me look like that." 1.18.4.

3.2 Theme two: The move to acknowledging MS.

At different points in the above process participants arrived at a point where they could acknowledge that they had MS. Analysis of the interviews revealed how acknowledgement had different meaning to different individuals. Mary explained what this meant for her:

"I suppose by then I'd accepted that it was something that I'd got and would never get rid of.. I suppose I did realise that it was something that would be with me for ever." 1.10.14.

She went on to explain in more detail what the implication of this was:

"But I think that I've now realised I've had to sort of gear my life taking the MS into consideration, whereas before probably a few years ago I didn't." 1.10.20.

Ian explained how he felt acknowledgement occurred gradually and was defined in terms of function:

"But I suppose one adjusts without realising that you do it. I think you end up being aware of what you can and can't do." 3.21.8.

Another component of acknowledgement was having to plan life to fit in with the demands of MS. Kathy explained that she had wanted to go on holiday with her daughter but because she was incontinent and had to self catheterise she had to plan her trips carefully:

"I have to work out how long it is going to take me to get there.. will I last that long." 5.13.14.

Mary explained how in the past she would spend all afternoon in the garden and not be able to get back in. Acknowledgement meant to her that:

“I am getting more sensible now.. if I do that it is going to bite back.” 1.11.16.

Irene also showed how acknowledgement contained an element of loss about future ambitions:

“Well I suppose that I realised that I was not going to be able to do everything that I wanted to.” 9.3.11.

Examination of the term acknowledgement reveals that it is different from the term acceptance. Acceptance implies an end state whereas acknowledgement implies a middle point between denial and acceptance. Participants defined acknowledgement as realising that they had MS, that it required planning around and that it implied limitations but that it did not imply giving up. The importance of this distinction was seen in the relation of the term acknowledgement to the next theme, that of an active coping stance towards MS. Acknowledgement was required before an active coping stance towards MS was possible.

3.3 Theme three: An active coping stance towards MS

It is necessary to acknowledge the existence and effects of MS before it is possible to develop an active stance in order to deal with the symptoms of MS and their effects.

The concept of an active coping stance towards MS included participants actively seeking to impose certainty over an uncertain disease process and actively developing strategies and a fighting stance towards the disease process.

i) Making sense of uncertainty

A diagnosis of MS does not provide any certainty, the prognosis is uncertain and there is no cure. A central component of adjustment to emerge from the interviews was the way that individuals tried to make sense of the diagnosis or tried to impose some certainty to the disease process. One way participants did this was by seeking out information about the disease. Some did this through the MS society, others sought out books on MS. Very few participants received information from the health service and they had to seek out information individually. Bill explained how such information helped him make sense of what was happening to him physically:

"So of course I put it (initial symptoms) down to tiredness until I read the books on it." 7.4.24.

However, information only provided a general picture of MS. Most participants felt that their MS took a very individual course. In this situation the only way to understand MS was through personal experience. Again the interviews showed how individuals tried to impose meaning and certainty on their experience. One way of doing this was to try and understand what triggered relapses. Mary felt that medical procedures triggered her relapse:

"I've only probably had one or two major relapses and I think one of those was caused by having a tetanus injection.. I was suppose to have three boosters and on the second one I had a relapse and I'm sure that was the cause of the attack." 1.9.16.

Over time individuals got to know how their MS was progressing. John explained how he became aware of the physical feeling before an attack would occur:

"There are days where you get up .. it usually shows when I get up to go down to make a cup of tea. I'd get downstairs and think oh God here we go again .. the legs are playing up, they feel as if they haven't got any strength in them." 4.12.2.

Kathy explained how she and her husband developed a procedure for predicting when an attack would occur:

"Before I would have an attack I would say to my husband 'I can't feel my legs properly' and he would get a needle and stab it.. and sometimes he would say 'it's not

too bad in this part of your leg .. but that part is worse.. there's not too much feeling there etc." 5.11.4.

She went on to explain how she would then alter her behaviour if she felt a relapse period was starting:

"I would go to bed .. I would not push my luck I'd just go to bed and think well here it comes and I'd wait for it." 5.11.10.

ii) A fighting stance towards MS

Another way in which the process of adjustment to MS became an active process was seen in the way that certain individuals developed a stance and strategies for fighting the disease. Some of the accounts suggested a fighting stance was needed in order to avoid the disease taking over. Keith explained:

"I think I've got to try and get out more, you know exercise more even though I don't feel like doing it.. but I feel I've got to do it. Maybe it's the fear of the unknown again and maybe I feel if I don't do it I won't be able to do it in the future." 2.14.14.

Kathy highlights how fighting was essential to avoid further deterioration:

"I can't let go of my independence.. I think if you give in to it and let everybody do everything for you you will end up like a cabbage anyway." 5.19.26.

John summed up his attitude to MS as:

"I mustn't give in and mustn't make concessions unless they are absolutely necessary." 4.16.17.

In practice John did this by not relying on adaptations or help. He explains why he did not get a stairlift installed:

"that again would have been a retrograde step.. You come to rely on it. Instead of really trying to get up the stairs you would say 'oh this is nice and easy' and you wouldn't make the effort." 4.14.27.

Another element to the concept of fighting was the way in which participants developed strategies in order to maintain former activities or roles. John explained how he developed a strategy to enable him to continue going into town with his wife:

"So now what we do is there is a bus stop just down the road.. we have this folding seat.. My wife carries that and I have my elbow crutch. We get on the bus and then we get down town and then we walk a little way and then I will stop and sit down for a few

minutes.. carry on a bit more. So we haven't completely cut ourselves off from going out .. it is with great difficulty but we still manage it.. And it gives us the chance of going out together." 4.10.15.

Kathy explained the importance of being able to do housework despite the struggle:

"I've got a stairlift and I was bringing it down a couple of stairs at a time and then I would bend over and sweep those stairs.. I'm quite glad that I can sweep down these stairs it sounds silly but it makes you feel proud that I can actually do it." 5.2.14.

In summary participants' accounts showed how individuals actively shaped adjustment by finding out information, imposing regularity and certainty and by adopting a fighting attitude and strategies.

iii) Emotional reactions

As well as taking an active stance towards MS there were times when individuals became depressed and upset in reaction to the effects of MS. This was difficult to examine at times because many participants did not talk about their emotional reactions, a point I will explore in the discussion section. Even when participants did talk about their negative emotions they talked about their fighting stance. Keith explained how he fought against negative feelings:

"Sometimes you're down and other times you're up so you think positive .. I think that's what you have got to watch.. you've got to try.. You've got to try and be positive all the time.. think of the positive rather than the negative." 2.14.10.

Mary showed how sometimes this was too difficult:

"I mean I do get depressed over it and there are times when it reduces me to tears .. frustration really." 1.10.18.

3.4 Theme 4: Adjustment within the social context

Another major theme from the analysis was the way in which individuals have to work out their adjustment within family systems and social systems.

3.4.1 Family adjustment

Analysis of the interviews suggested there were two concepts regarding family

adjustment. These were adjusting roles within the family and communicating about the MS.

i) Role adjustment in families.

A number of participants talked about their partners supporting them and going through the process together. One aspect of this process was the ability of individuals to adjust their roles with the family and their role expectations of others. This was highlighted when participants became more disabled. In these instances partners had to adjust their roles in relation to each other. Kathy explained how she and her husband had adjusted their roles:

"He has helped me get on a bedpan which I'd never have thought he would have done. That just wasn't him but he did it. All personal things he has had to do for me but he's not moaned and he's been wonderful." 5.19.11.

Also individuals had to adjust to taking a more dependent role. Bill highlighted this:

"She has adapted very well.. And she must love me a great deal to put up with me.. She has to wash me, change me, shave me, feed me, hold me cups of coffee... she has to do everything for me literally." 7.5.21.

Participants rarely discussed relationship difficulties in the first two phases of the study.

However, Mary provided some insight into the difficulties in adjusting roles in sexual relationships:

"But I do feel that it is my fault .. Is it because of the MS that he has got this psychological feeling deep inside him .. that I'm ill and that I'm different.. I feel that I'm not as attractive as I used to be and I'm staggering around and not as independent as I was.. My life is not the same and what could he see in me." 1.25.13.

ii) Communicating about MS in families

Another concept identified from the interviews was the difficulty families had talking about MS. Mary talked about lack of communication with her son:

"Very rarely does he ever speak or do I speak to him about MS. He is a very deep thinking sort of chap." 1.13.3.

She went on to explain her reason for not bringing up the subject:

"I'm always anxious that they (both children) shouldn't worry about me. I try not to worry them about it." 1.14.18.

In many families talking about MS with children and other relatives seemed to be particularly difficult. Part of that difficulty may have been because there is a small genetic risk (Thomas, 1996). Mary said

"One of her (daughter) first reactions was 'am I likely to get it?' and I could honestly say I don't know." 1.14.10.

3.4.2 Adjustment within a wider social context.

i) Communicating about MS.

The difficulty in talking about MS also seemed to extend beyond families to wider social interactions. Mary described the problem well:

"I suppose I don't want to bore people by telling them what I know about MS so I tend to avoid talking about it...Sometimes someone say's to me point blank 'why are you in a wheelchair?' If it's someone I don't know and I'm never likely to meet again I just say 'oh I've got something wrong with my leg'..I don't like going into all the complicated details of MS." 1.16.17.

Kathy explained how she doesn't tell others how she is feeling:

"And people say to me very often on the phone 'how are you?' and I say 'I'm fine' I could be in bed feeling awful but I say 'I'm fine' I never say 'I'm not well'." 5.15.19.

One of the reasons for this may have been because participants did not want to be treated differently because they had MS either by being pitied or patronised. Keith explained:

"Well I kept it (diagnosis) to myself apart from very close friends. I didn't tell people about it because I wanted them to accept me as Keith and not poor Keith with MS." 2.5.7.

Sometimes participants found that others would try to help or make allowances because they had MS which many participants found patronising. Keith again explained about an incident that happened to him:

" I told my boss a few years ago .. and he used to feel guilty because it was a busy job and he would pile the work on.. and occasionally he used to say ' I shouldn't be giving you all this because you have got MS' and I'd say 'look I've told you if I can't handle it I will tell you'." 2.7.3.

When participants became more obviously disabled they were often treated in a patronising way. Peter talked about this:

“What does annoy me about it is if somebody is talking over me.. If somebody would come in and say ‘ would Peter like a cup of tea?’ and I’m sitting here about two or three feet away and instead of asking me they would ask you.” 8.3.20.

Another reason not talked about could have been the threat of rejection due to the stigma of having MS. This was not talked about much but Irene described how she had experienced this:

“But one of (husband’s) friends .. he stopped coming round .. so (husband) said you can’t catch it.. He would cross the road to avoid us.” 9.5.19

Also MS was not talked about between individuals with MS. This may have been part of a denial or avoidance strategy by some people. It may also have been a distancing strategy from the worse case scenario concept. Ian talked about how this lack of discussion about MS seemed to occur at an institutional level in the MS Society:

“The branch seems to do a lot at the social level .. I mean organise outings in the summer um .. but there doesn’t seem to be.. I thought people would get together and talk about MS.. but there doesn’t seem to be any of that at all...the only time you sort of got to talk to other people when you meet them on the social level and then it’s a very superficial level.” 3.18.14.

Research aim 3 To develop an account of the way that service use fits into the adjustment process.

3.5 Theme five: Service use

The analysis of the interviews also revealed that participants go through a process in terms of their service use.

i) The medical approach -hopes for a cure

For all the participants the initial contact with the specialist medical service was at the time of diagnosis which involved detailed assessment and the use of modern equipment

such as brain imaging scans. This initially led to a sense of hope and belief in medical progress. However over time nearly all the participants became dissatisfied with the medical approach. Irene described her initial thoughts at diagnosis:

"I thought there would be a cure and he said there is no cure but they are trying to find a cure." 9.2.12.

Participants found initially that there were treatments available to relieve symptoms and many found initial benefit from the use of steroid treatment. However, after a while most participants found the effectiveness wore off.

ii) The medical approach- A gradual disillusionment

Over time experiences such as the above seemed to lead to a gradual disillusionment with the medical approach. There were many quotes such as 'there is nothing they can do'. Individuals have to live with MS for many years and have to visit hospitals over their lifetime. Many participants were disappointed with the lack of continuity in the healthcare system. Keith explained:

"The hospital feels too distant.. Well it isn't the physical mileage they just feel too distant. They have so many customers shall I say.. I just feel as though I am a number." 2.13.8.

In response to this disillusion with the medical approach some participants sought out alternative treatments. Kathy found herbal treatment very effective:

"The doctors have told me that they can't do anything about it.. which.. my husband's very much like me.. he's a bit well there has to be something.. Somebody put us on to this herbalist .. so we said OK we'll give it a go.. it can't be any worse than the doctors because they can't do anything.. So um I got onto him.. he gave me some capsules and he put on a special diet.. but I was in a wheelchair and he got me out of the wheelchair and hubby helped me learn to walk again." 5.2.22.

Several individuals also talked about how cannabis had helped them to relieve symptoms*

This shift from passively accepting medical help to actually seeking out alternative approaches (some of which are illegal) reflects the individual adjustment process where there was a move from a stance of passive denial at pre- diagnosis to an active coping stance later.

iii) Self organisation- The voluntary sector

From the interviews it seemed that the voluntary sector filled some of the gaps left by the lack of other services. They provided continual service from diagnosis onwards.

Kathy explained how the welfare secretary provided a source of continued support when needed:

“She is always on the end of the phone.. that’s nice to know that there is always someone on the end of the phone.” 5.18.12.

They also provided some services that were not provided by healthcare and social services. Mary said:

“The MS society were very good. They gave me free sessions at (private clinic) hydrotherapy once a fortnight.” 1.22.12.

However, the MS society was not seen by everybody as ideal. It is a voluntary body and service provision depends on the contribution of volunteers. At the time of the study the local branch was thriving and very active, however Vera (who had had MS for 40 years) explained that in the past it had ceased to exist through lack of support.

In addition a number of individuals may not want to join. Keith explained:

“I’ve joined recently.. the last few months the MS society.. and the welfare officer came round to see me a few weeks ago, but I don’t have any contact although I’ve been invited to the functions I haven’t been.” 2.11.16.

* quotes were not used here to preserve anonymity. Because although cannabis is seen as medically helpful for individuals with MS it is illegal in the United Kingdom.

The MS society is also a charity and several participants hinted at their unease from accepting support from a charity. Kathy explained:

"I do knit for the MS so that they can sell whatever I knit and it helps them make money etc.. Yes they give me and I give back.. because I don't like being on the receiving end and not giving back." 5.18.10.

Again this unease about accepting help from the MS Society could be because it runs contrary to the active coping stance adopted by many people with MS. It also contradicts the social process of not wanting to be treated differently.

Summary

An analysis of participants' service use suggests that there is a move from reliance on medical services to more social and self help type services. This process could be a reflection of the individual adjustment process from a passive stance to an active coping stance.

3.6 Evaluation of the analysis through theoretical sampling.

In phase three of the research the notion of theoretical sampling was used to evaluate the analysis. A second interview schedule was developed which was based on the themes that emerged from the initial analysis (Appendix 12) and four more participants were interviewed. The accounts from these participants were compared with the themes from the initial analysis.

3.6.1 Theme One: Individual experience MS as a series of different phases

a) Pre-diagnosis phase

There was general support for the notion of a phase in which symptoms were present but the participants adopted a denial or avoidant stance towards them. Julie, Barbara and Pam all had a history of strange bodily sensations for a long period before diagnosis. Charles felt that his MS had been more sudden with bodily sensations appearing just a few months before diagnosis.

b) The diagnosis phase

Again there was support for the notion that the concepts of communication of diagnosis had an important effect on psychological adjustment. Barbara had been told 'well you know that you have got MS' by the consultant when she had no idea at all. This had a considerable impact on her and she was still visibly upset about this at interview twelve years later. In contrast both Charles and Pam felt the diagnosis had been given helpfully and this, combined with the diagnosis not having much meaning for them, meant that it had had little apparent psychological impact for them.

In terms of the worse case scenario, both Barbara and Pam talked about MS as a fatal disease based on images which clearly made them anxious. Pam had a friend who died last year who had been diagnosed at a similar age to Pam. Barbara talked about how her family had mentioned people dying with MS.

c) The remission phase

There was support for the notion that long periods of remission lead to a denial stance and a difficulty acknowledging MS. Charles talked about how initially he did not want to believe that he had MS and that he had hoped that he would wake up and find that the doctors had made a mistake. This belief was not challenged while his MS did not progress.

d) The relapse phase

There was support for the notion that gradual acknowledgement occurs as the effects of MS become more visible and pronounced. Charles found that over time as he became more disabled he came to a gradual realisation that his MS was real and was affecting him. Pam felt that her gradual deterioration had helped her to get used to her MS over time. Barbara also talked about adjustment as a gradual process.

e) Rapid change

There was support for the notion that sudden changes resulted in a different process to gradual change. Charles was suddenly 'pensioned off' from his job because he could no longer work effectively with his MS. He felt that this was 'another blow' which required additional adjustment. Julie had suddenly lost the use of her legs a year prior to interview. Although she did not know that that this was permanent at the time, she found it very difficult to get used to the idea and carry on with her former lifestyle.

f) The loss of mobility

Again there was support for this as a separate phase in the disease experience. Julie after years of having few symptoms, suddenly had to use a wheelchair and found it difficult to go out because she felt anxious and self conscious. Barbara confirmed that using a chair affects the way other people treat you.

3.6.2 Theme two: The move to acknowledging MS

Again participants talked about reaching a state of acknowledgement of their MS. Barbara felt that at first she was not able to admit to herself or to others that she had MS. To her, acknowledgement was about being able to think and talk about MS. She also said she no longer got upset when talking about MS which suggested that she had gone through an emotional process of acknowledgement. Charles acknowledged that he had MS, took it into consideration in long and short term plans and said he no longer thought about it unless he was having a bad day.

3.6.3 Theme three: An active coping stance towards MS

Two of the participants in this third stage appeared to adopt an active and fighting approach towards their MS and the other two participants did not. Barbara talked about seeking out information and developing strategies for keeping her mind active. Charles managed to go out everyday and did tasks for himself. Despite struggling he planned his shopping so that he was able to carry it back to the car. Both Pam and Julie did not seem to adopt an active fighting approach to adjustment and appeared to

be the most psychologically distressed. This suggests that adopting an active coping stance may be necessary to stave off a negative psychological reaction.

3.6.4 Theme four: Acceptance within the social context

i) Family adjustment.

Again there was support for the importance of adjusting family roles and of communicating about MS in the family. Barbara and Pam both felt that their husbands had adjusted and took on caring roles. In contrast, both Charles' and Julie's marriages had broken up. Charles felt that MS was responsible in large part. He said his wife had been bitter about the MS and they had not talked about it. Julie felt she could not cope with looking after husband and children as well as having MS. This suggests that her husband had difficulty in adjusting to a new role of helping his wife. In terms of communication, Charles felt his sons had taken the news of his MS badly and had difficulty talking about it. Julie explained that her twin sister and her father would not talk about her MS and had not visited her much.

ii) Wider social adjustment

There was some support for the notion that individuals with MS perceive other people as treating them differently because they have MS. Barbara talked about other people feeling sorry for her, which she disliked. Charles hated other people trying to help him when he had not asked them to. Again this reflects a conflict between being helped and adopting a fighting stance. Julie on the other hand had kept her friends from before and didn't feel they treated her any differently.

In terms of communicating with other people with MS there was support for the finding that some people did not want to do this. Julie, Barbara and Pam had little contact with others with MS. Julie said she did not want to talk with others with MS as she could not cope with their problems. Pam said she had enough to do with her family and Barbara said that she was not 'that sort'. Charles who did meet regularly with other people with MS said that they never talked about MS.

3.6.5 Theme five: Service use

There was some support for the idea that individuals move from a reliance on a medical solution to their problems to a self help approach. Pam did not see the neurologist because she felt there was little point. Julie felt that the doctors could do nothing for her. Two out of the four participants used cannabis to relieve their symptoms. Barbara used a chiropractor. She had also just begun to see the local neurologist and was finding it helpful. The importance of continuity of service was highlighted by Barbara and Charles who both felt their GPs had been important in providing support on a continuous basis.

In terms of the MS society Barbara, Pam and Julie had minimal contact. For Pam and Julie this seemed to be due to distancing from the worse case scenario rather than rejecting help because it was not compatible with a fighting attitude. Charles found the MS Society provided a helpful source of support and he enjoyed the social outings.

Conclusion to phase three

This phase highlighted the extent of individual variation but still offered support for the broad notions of phases of MS and adopting an active coping stance. There was also elaboration of some points such as the notion that acknowledgement may occur in response to gradual deterioration. Most importantly there was the suggestion of the ways that the adjustment process may go wrong, for example that not adopting an active coping stance may lead to a poorer psychological outcome and not being able to adopt new roles and communicate about MS within families may lead to relationship breakdown.

4.0 DISCUSSION

Overview

The aims of this research were to construct an account of the process of psychological adjustment to MS, including individual and social processes and examining the way that services fit into this process. Results suggest that, despite much individual variation, participants appear to experience many common processes as they adjust to having MS. The discussion section will draw together these broad processes and compare them with the existing research literature. The section will then explore the limitations of this study and use the qualitative evaluation concepts as a basis for a critical review. Finally, conclusions will be drawn along with implications for further research, for service implementation and for clinical practice.

4.1 The individual process of psychological adjustment to MS

i) Adjustment in terms of taking a personal stance towards MS

The results suggest that one way of understanding psychological adjustment to MS is by examining the way individuals change their stance towards the disease over time.

The basic process is one of changing from a denial or avoidance stance to a position of acknowledgement of the disease. Acknowledgement means realising that the MS is not going to go away, that it has an effect on the person's life and that it needs to be taken into consideration when planning short and long term goals. This process takes place at different times for different individuals. For the majority acknowledgement comes in response to the effects of the progression of the disease over time. It is a gradual realisation. Reaching acknowledgement allows an active coping stance towards the disease and its effects. This active stance includes finding out about the disease, making sense of personal experience and adjusting behaviour accordingly and most importantly adopting a fighting attitude and stance towards the disease. At times such a stance is subject to setbacks and individuals oscillate between periods of frustration and psychological distress and periods where they are fighting the disease.

This account of the process suggests that the early research in which responses to MS were seen as a passive process either because of a set personality pattern or because individuals only react emotionally to the disease are problematic. The findings from this study are more in line with recent studies such as Matson and Brook's (1987)

model about individuals with MS adopting an active managing approach towards the disease.

ii) MS as an experience of moving through a series of phases

The process of adjustment in terms of the move from a stance of denial to a state of acknowledgement and active coping takes place against the background of the overall experience of MS as series of phases.

The initial phase is the period of pre diagnosis during which individuals experience strange bodily sensations sometimes for months or years. An avoidant or denial stance is predominant during this phase as individuals do not do anything about the bodily sensations. At some point individuals move to an active stance and seek medical advice.

The second phase, diagnosis, depends to a large extent on the meaning the disease has for people. If the disease has little meaning individuals can still choose to ignore or avoid facing the consequences. For some, an acknowledgement of the disease can come at this point and they seek out information and understanding. For others diagnosis carries a meaning of the worse case scenario which is an image or idea of MS as a disease leading to disability/dependence and possible premature death. Again individuals take a stance to this which is commonly one of distancing or avoiding thinking about the possibility of the worse case scenario. As the disease progresses meanings change and develop. A number of individuals continue to use the worse case scenario image as a comparison for how their MS is progressing.

Communication of diagnosis is a important factor influencing adjustment. The way it is handled can affect immediate psychological reactions, the way families adjust to the diagnosis and longer term relationships with the doctor.

The way that individuals with MS experience progression after the diagnosis is highly variable but is important for how they adjust to the disease and its effects. As stated in the introduction there are four broad patterns: Relapse-remitting, progressive, rapidly deteriorating and benign.

The remission phase is again highly variable with some individuals not experiencing remission and others having periods of remission for many years. Periods of remission allow individuals to go back to everyday living. For those in remission for long periods of time, there is little need to acknowledge the MS and they can continue to take a stance of denial or avoidance.

The relapse phase can be a regular occurrence for one or two months a year, or a more regular occurrence every month or a continuous occurrence with no remission phase. If the relapse period is for a short period it can initially be experienced as a period of ill health which when over leads to a longer period of normal living. Again it is possible to take an avoidant or denial stance at this phase. However, over time there is a gradual deterioration in ability leading to permanent disability. Realisation of this often occurs when individuals find that they can no longer undertake the activities that they

used to be able to do. This creates a pressure for acknowledgement of the disease as it becomes harder to avoid or deny.

Sudden changes occur at different phases which forces individuals to confront the disease and its effects. Sometimes these changes lead to a period of crisis in response to loss. Individuals can then either take a active coping stance or a denial stance to the consequences of the sudden change.

The movement to a phase of using physical aids also adds pressure to acknowledge MS. During this phase individuals move from experiencing MS as a largely invisible disease to experiencing MS as a visible condition. Adjustment has to take place on a social basis, as individuals are perceived differently and often treated in a rejecting and patronising way.

The nature of this continuous process through different phases with different meanings suggests that previous research which conceptualises adjustment to MS as a single process is inadequate. The results from this study would not be accounted for by Matson and Brooks' (1977) theory based on a bereavement model. With MS there is no single event such as the loss of a loved one. After diagnosis there may be a variety of different experiences. Also it is a continuous process in which individuals get use to one phase and then the situation changes again. Sometimes there is little time to get used to each phase. There is also no end point to the adjustment process as individuals can always move on to another phase. This finding is also problematic for the numerous studies that have looked at adjustment as an outcome. Results of

adjustment as an outcome would depend at what phase individuals are at, and this is likely to change over time.

iii) Defining good and bad outcomes

The notion of adopting an active coping stance towards the disease also highlights the difficulty of defining what constitutes a good and a bad outcome in adjustment terms. Previous studies have seen the adjustment process as culminating in acceptance of the disease (Antonak and Livneh, 1996). Again this is similar to a bereavement model where the person accepts that loved one has gone and the task is to move onto a new life. However the notion of acceptance suggests an end point. In this study the term acknowledgement is used because it suggests a mid point between total denial and acceptance. For individuals with MS a certain amount of denial may be seen to be a good outcome. Acceptance could be seen as giving into the disease and contrary to the notion of fighting the disease. Acknowledgement allows and is necessary for an active coping stance to be adopted.

Also acknowledgement is a more useful concept for those who have an image of the worse case scenario. Acceptance might mean accepting the worse case scenario as an option which would be intolerable for most people. A more helpful option might be to distance oneself from this image. The findings suggest that adopting an active coping stance may protect individuals from the negative psychological consequences that are likely to occur from a continuous deteriorating and disabling condition. This idea explains Matson and Brook's (1977) finding that individuals have higher self concept scores as MS progresses. It also supports Robinson's (1990) findings that many

individuals with MS construct positive and optimistic accounts of their experience in spite of disability and deterioration.

4.2 Social adjustment to MS

The findings suggest that the individual process above is encased within a social context. In families two central issues seem to be the concept of role adjustment and the difficulty of communicating about MS. Difficulty with these two areas seems to lead to relationship problems. This supports Matson and Brooks (1987) findings that managing is about re-negotiating relationships.

The difficulty in talking about MS extends to the wider social context in terms of difficulty talking to friends, strangers and other people with MS. According to previous research (Matson and Brooks , 1977) being able to talk about MS and accepting help from others is central to accepting the disease. However from an active coping stance, not talking could be seen as important way of coping. Most people experienced being treated differently either when other people knew they had MS or when they could see that they had MS. Adopting a fighting stance means not being pitied or treated differently. The problem with an active coping stance is that not talking can have an effect in terms of intimacy of relationships. However, many people felt it was crucial to talk to their partners. This shows that partners also need to reach acknowledgement in order to support the person with MS. This again supports Matson and Brooks findings about family adjustment.

4.3 Service use and the adjustment process

The third aim of the study was to examine how medical and support services fit in with the process of adjustment to MS. The finding suggested that individuals go through a process of service use as their MS progresses. Initially there is faith in medicine for treatment or a cure. Over time however, there is a gradual disillusionment as the medical approach is not perceived as helpful. Individuals turn instead to alternative treatments and self help approaches. This process reflects the move from a passive stance waiting for a cure or treatment (denial in individual process) to an active coping stance where individuals seek out help and alternative approaches.

As well disappointment with lack of a medical cure, individuals were also disillusioned with current healthcare practice which is mainly geared to acute care. Therefore there was a lack of continuity and of support in the long term. This supports Earl (1995) who argues that chronic neurological illness needs a separate service provision to acute illness.

The MS society does provide continuity, support and help. However, again some individuals find this difficult to accept as it runs counter to an active coping stance.

4.4. Comparing the results with other models of adaptation to chronic illness

In this section the results from the study will be compared with two influential models of adaptation to chronic illness in general. These are the cognitive coping model

(Folkman and Lazarus, 1985) and the self regulation model (Leventhal, Meyer & Nerenz, 1980).

The cognitive coping model is based on the assumption that chronic illness is a source of stress and that individuals use coping strategies in order to adapt (Folkman and Lazarus, 1985). According to the model individuals firstly evaluate the threat posed by the illness and then secondly make an appraisal of the personal, social and environmental resources available to cope with it. Personal coping responses are classified into problem focused strategies which include active coping, planning, suppression of competing activities and seeking support, and emotional focused strategies which include positive reinterpretation, venting emotions, seeking emotional social support, turning to religion, acceptance and denial.

The cognitive coping model is similar to the theory developed in this study in that it suggests that rather than having an end point in the adaptation process there is a constant cycle of coping with different events. Also it is similar in that it suggests that adapting to illness is an active process rather than a passive reaction to events.

However, the coping model does not explain the process of adaptation over time. The results from this study suggest that individuals with MS change coping strategies from denial/ avoidance to acknowledgement as the disease progresses which in turn allows other coping strategies such as fighting the disease to develop. Also the coping model suggests that strategies such as denial and acceptance are discrete categories of response, whereas the results from this study suggest that individuals show elements of

denial and acceptance simultaneously and are better thought of in terms of acknowledgement.

The self regulation model (Leventhal, Meyer & Nerenz, 1980) suggests that individuals create cognitive representations of illness which give personal meaning to the symptoms which they experience and act as a framework for guiding and evaluating their coping efforts at dealing with the illness. The model proposed that illness representations can be categorised along several dimensions including identity (the label and symptoms of the disease) , the perceived cause of the illness, the time line or how long the disease will last, the consequences of the disease on the person's life and the beliefs people have about the curability or controllability of the illness.

Again the results from this study are similar to the self regulation theory in that they highlight the importance of defining MS according to personal meaning rather than in terms of objective characteristics when examining the psychological aspects of MS. However, by attempting to explain all chronic illness according to certain dimensions the self regulation model ignores characteristics associated with a specific illness such as MS. The results from this study suggest an important shared meaning among individuals with MS is the shared image of the worse case scenario, which is not accounted for by the self regulation model.

Another finding from this study which is not accounted for in the self regulation model is the way that individuals construct meaning using others peoples experience, using information and most importantly from their own personal experience. This in turn

suggests that meaning is constructed over time and is subject to changes over time which again is not accounted for by the self regulation model.

In summary the results from this study support some aspects from other models of adaptation to chronic illness. However, the results also provide additional explanations not accounted for by other models. These include the development of adaptation over time, the notion that the coping responses of denial and acceptance coexist under the term acknowledgement, the ways in which the personal meaning of MS develop over time and additional characteristics of personal meaning in MS such as the imagery of a worse case scenario.

4.5 Limitations of the study

Despite meeting the research aims and producing an account of the psychological process of adjustment to MS the study suffered from a number of limitations. The study could be criticised from a traditional research point of view for not producing a reliable account. The organising and selecting of concepts from participants accounts in order to create a theoretical account required substantial subjective interpretation. An inter rater reliability check was not undertaken because in grounded theory it is necessary to devise theoretical concepts (which necessarily require interpretation) as well as descriptive concepts. As was argued in the introduction to this study no claim was being made to a single universal truth. Any reliability check would therefore depend heavily on who was undertaking it. The issue of being open about the subjective process is explored in the concepts of Reflexivity and Auditability below.

Another related criticism of the study is whether the results can be generalised beyond this population. The author's account was based on a small sample of individuals with MS. This was due in part to some difficulties with recruitment. However, in order to undertake an in-depth examination of participants accounts in a limited time frame a small sample was necessary. While attempts were made to seek out individuals with a variety of characteristics through the notion of theoretical sampling, some people were underrepresented. Most notable was the lack of newly diagnosed individuals with MS, of younger people with MS and the lack of individuals with rapidly deteriorating MS. Also many of the participants were connected to the MS society. These individuals may have been more likely to develop a active coping stance (Although several did not). This weakness is offset by the notion that in grounded theory the theoretical ideas can be generalised rather than the population characteristics. The notion of how far these results can be generalised is examined through the concepts of Respondent Validation and Rhetorical Power below. However it is acknowledged that before any claims are made to wider generalisation the account needs to be tested on other samples.

4.5 Evaluation using qualitative criteria

The following section evaluates the research using criteria introduced in the introduction which is traditionally used to evaluate qualitative research.

Auditability

This refers to the notion of opening the research process up to scrutiny (Sandelowski, 1986). This was addressed through the use of a research diary (Appendix 1) which

documents the steps and decisions taken by the researcher and highlights the personal side of the research. This explores the decision making behind using qualitative methods to study MS. It also explains the way that the analysis was undertaken. It is hoped that while the study contains subjective interpretative processes, these are not obscured, so that the reader can see how the conclusions were reached. The diary also details the personal process of undertaking the research, including the difficult nature of interviewing individuals with a distressing condition, with little help from services. It is hoped that this will reveal the human process behind the research and in turn provide a more valid account of the research process.

Respondent Validation

This refers to the idea of allowing participants to judge the validity of the theoretical analysis (Silverman, 1993). Participants were sent a summary report of the initial analysis along with a feedback sheet. One person was not sent a copy because he had moved and his address was not available. Of the remaining participants nine returned the forms and one rang up because he could no longer write (response rate of 77%). The full comments are in Appendix 15. All the participants who sent back feedback agreed with the analysis. Most commented that they felt the interview was conducted well and nobody had any criticism of this. One person felt that a written response would have produced more accurate data because of the difficulty of talking about MS face to face. Some participants suggested additional material for the theoretical account and this was added where possible. Silverman (1993) has suggested that the concept of respondent validation is problematic because of the inherent power difference in the research process. Participants may be inhibited from criticising or

challenging the account produced by the ‘expert’ researcher. However, analysis of the participant’s comments showed that they had thought carefully about the account and there were some constructively critical comments suggesting that they had not just passively agreed with the author’s account. While Silverman’s criticism of respondent validity suggests that the concept of can not be the sole criteria for evaluation, as part of a series of evaluation criteria it adds to the argument that the results can be generalised beyond the researcher’s interpretations. It is also beneficial from an ethical view in allowing the participants to actively participate in the research process and giving them a voice in the process.

Rhetorical Power

This concept examines how persuasive the arguments in the research are to others (Henwood and Pidgeon, 1995). This was addressed by sending a copy of the results section to a clinical psychologist working with individuals with MS and not connected to the study or the service from which participants were recruited. He was asked to provide feedback from a clinical point of view. The feedback from the psychologist is reported in full in Appendix 16. This feedback was generally positive. It was felt that the theoretical account succeeded in providing a model of adjustment and fitted with new research in the bereavement field. Also particular parts were useful including the notion of an active coping stance and notion of the worse case scenario. Limitations of the study were that it was a good model for relapse remitting MS and that another model may be required for rapidly deteriorating MS.

A copy of the summary report was also sent to the welfare secretary in the MS society for her feedback (Appendix 17). She agreed with the analysis and in particular the importance of the way that the diagnosis is communicated.

Although the feedback was limited in that it came from two individuals, it does provide, along with comments from participants, evidence that the account of adjustment to MS can be generalised beyond the immediate study. It is hoped that this feedback process will continue with reports to the MS society and to local services.

Reflexivity

This addresses the extent to which the researcher reflects on the process of his or her research (Stevenson and Cooper, 1997). This was addressed in part through the research diary and in part through a further analysis of the text which is presented below:

i) Reflexive analysis

In exploring participants' accounts of experience I was attempting to understand the 'insider's' perspective about psychological adjustment to MS. However, as Salmon (1996) argues, participants' placing of researchers into a certain position in terms of social and cultural stance can often be more influential than that from which researcher believes he or she comes from.

From the start the research presented a dilemma for me. I was attempting to understand and position myself on the side of the participants'. In the main, participants' experiences of living with MS had been without professional help or interpretation. Many had actually received quite negative experience in their dealings with professionals. I therefore wanted to place as little emphasis on my previous experience and professional background as possible. However, at the same time I also needed to impress the consultant, the MS society, the training course and the ethics committee and to show that I had experience and knowledge of the research area and that I was professional and competent. This tension was reflected in the interviews.

Analysis of interviews suggested that there were instances where I adopted a professional position and instances where participant's clearly placed me in that position. Ian who had had several negative medical encounters adjusted his discourse in the interviews when trying to explain points to me. For example when he was talking about his relapses he said:

"If your health level drops this leads to .. as you and as I am now aware .. this leads to your immune system getting low." 1.9.11.

Keith also adjusted his discourse to fit with his view of me when talking about his symptoms:

"And it was a number of years to tell you the honest truth before I started to feel tired or don't you use the word fatigued in MS circles." 2.6.1.

In analysing the interviews in retrospect my use of terms such as symptoms, remissions and relapses when asking questions and making points must have also contributed to being positioned as an expert.

Despite my intention to try and understand participants' experiences there were times when participants did not think that I could understand them. Kathy, when talking about the concept of coping, said:

"obviously in your position (directed to me) where you're not having to cope with it, you can't see how you cope with it.. but when you're there you don't think to yourself 'well how do I cope with it?' .. It's just something you've got to get on with." 5.14.8.

There was also a difficulty being in a research role rather than a clinical role, meeting participants for a one off meeting while trying to explore difficult issues with them.

Mary's discussion about research could have been easily directed at me:

"I get the impression that a lot of people who are doing research into this type of illness when they have got a spare minute.. I might be very wrong but I don't feel that there is a concerted effort." 1.23.8.

Despite trying to understand participants' experiences, in their own words analysis of the interviews reveals how my use of a psychology discourse directed the interviews at times. Also this discourse was often not shared by the participants. When I asked Mary how she felt at the time of first relapse I was enquiring into her emotional state.. she responded by saying:

"I was feeling not too bad again although I did feel just a bit weaker in the leg." 1.10.11.

Several other participants responded in a similar way. Talk about emotions did not seem to be present in many of the participants' discourses.

Also the analysis revealed the way that some of the questions I asked may have sounded like a standard psychology assessment. Again some participants seemed to be

expecting this from me. When I asked Ian how long he had been diagnosed he replied:

“I thought you would ask questions like that.” 1.2.1.

Analysis of the interviews reveals the way that participant accounts were constructed within a particular context. As a white professional male participants positioned me and responded in a different way than they might have done to someone else. Also despite my intentions to be non directional my background influenced the way that I asked questions and positioned participants. While this can be seen as a limitation to the study it also highlights the way in which researchers influence the research process. The role of a reflexive analysis such as this helps to reveal such processes rather than obscure them which it could be argued produces a more valid account.

5.0 CONCLUSIONS

The use of qualitative methods enabled an account of the psychological process of adjustment to be developed. This suggest that one aspect of adjustment is the move from a stance of denial to a sense of acknowledgement which in turn allows an active coping stance to be taken. This occurs against a background of experiencing MS as a series of phases. It is suggested that this stance may prevent overwhelming psychological distress in response to a continuously deteriorating and disabling condition. This process takes place within and influences the social context. A pattern of service use also reflects the individual adjustment process. The findings from this study have implications for clinical practice, service delivery and further research.

5.1 Implications for clinical practice

The theoretical account provides a framework for clinicians working with individuals with MS. It would be helpful to formulate on the basis of what phase of the MS individuals are in and what stance they take towards the illness. It would be useful to explore what images individuals have about MS and the meaning it has for them.

The findings that communication about MS within families is difficult suggests a systemic formulation would be useful. In terms of social interaction an understanding of how individuals see themselves in identity terms would be helpful.

From such a formulation different interventions could be planned. The findings from this study suggest that basing interventions on a self help approach encouraging an active coping stance would be useful. At the same time such a stance suggests acknowledging and dealing with the more negative feelings such as loss, fear, uncertainty is difficult for people with MS. A useful intervention may be to provide space to explore this side.

5.2 Implications for service provision.

The study shows how individuals experience MS as a long complex process through different phases with different concerns at different times. At present medical services are concentrated at the diagnosis phase. This is an important phase and how the diagnosis is conducted seems to affect future coping and adjustment. However the study also suggests that service provision is required at different phases over the individuals lifetime. There may be the need for information and support at the acknowledgement stage many years after the diagnosis. It is likely to be important to

be able to have access to services if mobility becomes affected. There may be other times when individuals have no need for services. This suggests the need for flexible service provision to be on hand when individuals need to access it. The need for continuity and a co-ordinated service is obvious. This could be addressed by developing specialist healthcare worker post or a multi-disciplinary team to co-ordinate service provision such as those recommended by the British Society of Rehabilitation Medicine (1987).

Difficulties in isolation and the benefits of learning from each other may be addressed by group approaches along the lines of the groups in Pavlou's et al's (1979) study.

5.3 Implications for research.

This research suggests that the experience of MS is a continual process of movement through different phases. Therefore research should use longitudinal methods where possible. Interesting questions arising from this study to be tested on a wider population include whether there is a process of movement from a avoidant/denial stance towards an active coping stance. It would be useful to know whether adopting an active coping stance results in better psychological or physiological outcomes. It would be helpful to know whether concepts such as the worse case scenario, difficulty in communicating about MS and the process of service use can be generalised to a wider population. It would also be useful to see if these concepts are present in other neurological conditions such as Motor Neurone Disease and other chronic illness.

In general because MS is such an individualised disease with a complex development and different meanings for different individuals large scale quantitative studies may not be the best way of examining the psychological aspects of MS. Qualitative studies are useful for looking at process accounts and the meanings people ascribe to their experience. This study had a broad remit and there is a need to look at other processes in more detail, especially the process of family adjustment. Finally there is an urgent need to examine service provision for people with MS in the UK.

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APPENDIX 1

Edited extracts from the author's research diary.

- 23.1.96 Start to think about the research. I need to read and present a research paper on an area that interests me in order to start thinking of ideas for the dissertation. I am interested in neurological disorders and think back to my time as an assistant psychologist, wondering how on earth people adjust to and cope with deteriorating neurological conditions such as multiple sclerosis and motor neurones disease. I Find a recent paper on psychological adjustment to Motor Neurones Disease based on quantitative measures.
- 25.1.96 Presented the paper to the group. After presenting it I feel that it does not really answer any of the questions that I have. How would this paper help me when seeing someone with MND. This sows the seeds of doubt about using a quantitative approach. I start to think is there another way of researching this area.
- 15.4.96. Research week- Over past few months I have decided I would like to try a qualitative approach to multiple sclerosis. I am interested in the process of adjustment and the meaning disease have rather than the characteristics of people with MS. The qualitative approach also fits with my interest in systemic and social construction ideas.
- 16.4.97 Met with Margie who suggests talking to different supervisors and to talk to Mario an former trainee who undertook a dissertation on MS but had difficulties with recruitment. Margie asked me lots of questions about taking a qualitative approach. What would be the use of the research? This is a question that haunts me for some time.
- 23.4.96 Rang Mario. He explained he had difficulty but was looking at couples and did not start research as early as I did. He made a number of useful suggestions.
- 30.4.96. I Have spent the last month reading Henwood and Pidgeon's account of grounded theory and Potter and Wetherell's account of discourse analysis. I feel very confused about the qualitative method. What am I trying to research, psychology or discourse.
- 7.6.96 Received a recent review paper on psychological adjustment to MS (Antonak and Livneh) through the library. I was looking forward to reading it but afterwards find it disappointing. The bulk of research seems to be looking for a universal emotional reaction to MS or a universal pattern of adjustment. There is little evidence for either so the paper calls for better measures, better sampling and better statistical methods. The paper contains little in the way

of new ideas and no framework for clinical work. Feels like it is written by researchers rather than clinician and suggests very little that relates to my experience. Makes me more determined to take qualitative stance.

- 9.6.96 Decided I would like a supervisor who is an expert in qualitative research. Rang Phil Salmon. She agrees to be my supervisor in principle but wants to me to write down my ideas and will see then. Relief that I have a supervisor but now I have to really get down to work and put ideas onto paper.
- 21.6.96 Phil Rang to say my paper has only just been forwarded to her. She was no longer based in London and that due to personal circumstances she can only supervise by post. I can not think of another supervisor who knows as much about qualitative research in psychology. I feel disappointed as I think I need personal supervision but glad she has agreed to supervise.
- 10.7.96 Rang Jos Kerkvliet a clinical psychologist who came to teach us and works with people with MS. He was positive about the research ideas and offered a number of suggestions. Feeling more positive.
- 18.7.96 Wrote a draft dissertation proposal for the course. Meet with Margie to discuss it. She suggests some minor changes but thinks it will go through OK.
- 23/7/96 Received a letter from Phil. She thinks the proposal fine but that I need to do a lot of work on the interview schedule. I seemed to have missed the point entirely as I produced quite a structured schedule. She also suggests putting off the decision about analysing the data. I feel worried about trying such a different methodological approach.
- 1/8/96 Handed in research proposal.- I wonder what the examiners will think of a qualitative approach..
- 6.8.96 Rang a local neuropsychologist about the possibly of recruiting participants. She felt she would definitely be able to get some participants and would talk to the neurologist. Gives me the contact details for the local ethics committee.
- 23/9/96 I have written the participant information sheet, worked out the recruitment procedure and devised a new interview schedule. Struggle to send off the completed ethics forms in time. I am keen to get ethical application in early in case it fails. Send it off in time for the for meeting on 3/10/96.
- 28/9/96 The dissertation proposal has passed the exam board. I have to add quite a few bits. Pleased it's passed but anxious that qualitative approach is not fully understood.
- 30.9.96 Research week. Met with Margie and explain my worries about not having face to face supervision. She suggests I ask Brain Solts a former trainee who undertook a grounded theory analysis to be a backup supervisor.

- 2.10.96 A talk by Derek Blackburn on applied research makes me think a lot about generalisation. What is the point of a qualitative study if you can't generalise your findings? He talked about the idea of research as a basic framework rather than trying to explain all the detail which is not possible because of the complexity and individual difference. This makes sense to me in terms of qualitative approach.
- 3.10.96. am David Armstrong gave a talk about grounded theory and a study he published in the BMJ. Again reinforces the idea of a framework in which to understand. Make a definite decision to use grounded theory.
p.m. Gary and Brian two former trainees presented their experience of doing qualitative dissertations. Seemed hard work but possible and useful.
Arrange to meet Brian at a later date.
- 4.10.96 Presented my research ideas to the group. My presentation turned into a discussion about applied research and different philosophical approaches. Sue and Jan leading the group asked me a lot of difficult questions such as why not have a control group? Why use grounded theory in an area where a lot of research has already been done? Unsure of the answers .. need to do a lot more thinking.
- 6.10.96 Started a very busy placement in London with a two hour train journey to work. Wonder how I am going to get the research done on a day a week along with other submissions. At least the train journey will give me time to read.
- 10.10.96 Received a paper on a grounded theory study on MS by Matson and Brooks. They had previously written two important papers on MS using large scale quantitative research approach. If they have moved to a qualitative approach must be something in it. Enjoy reading the paper- full of insight.
- 17.10.96 Anxiety because I have not heard anything from the ethics committee. Ring the secretary who tells me I've got ethics approval. Massive relief one more hurdle gone.
- 5.11.96 Letter from Phil saying the interview schedule is much better. Relief
- 7.11.96 Met with Brian. Talk about qualitative methods and the role of reflexivity in research. Feel much more motivated. I asked him whether he would act as a back up supervisor. He will think about it and asks me to write to Phil to check it's OK with her. Agree to meet again. I hope he can as I found the face to face session really helpful.
- 14.11.96 Rang the neuro psychologist to go through the recruitment procedure. I will send information sheets and contact forms to her and she will give some out and send some to the neurologist.
- 28.11.96 Send off information sheets and contact forms and wait for replies.

- 20.12.96 Hand in small scale research project. Feel on target. The information sheets are out. I Feel I deserve a break over Christmas.
- 9.1.97 Christmas has not gone well. Both my mother and sister are seriously ill. I've heard nothing from the neurologist and am finding it very difficult to motivate myself. It's difficult to think about a project on chronic illness when illness is so close to home. Cancel appoint with Brian. Travelling to London is getting very difficult.
- 14.1.97 Received a letter from the neurologist saying that he was trying to find patients. At last something is happening..
- 23.1.97 Met Brian again. He agrees to act as a back up supervisor. He liked the research proposal. In supervision talked about thinking and being at two different poles. On one hand my interest in neuropsychology on the other this qualitative study. Physical v social divide which I find it difficult to reconcile sometimes. Also talked about approaching the local MS society for participants. Feel a lot better and more motivated after this session.
- 30.1.97 Hear from my first participant. At last get started. However I am still anxious about time. Despite getting ethics quickly don't seem to have made much progress over last three months.
- 31.1.97 Rang the local MS Society Vice Chairwoman. I think she was a bit surprised to hear from a psychologist interested in this area. She sounded quite positive and asked me to send written details and she will bring it up at next committee meeting.
- 3.2.97 In a ward round today discussing research re kidney donation. What the medical staff really want to know was what having a donated kidney meant to the child. A good example of where a qualitative approach would be useful.
- 8.2.97 Started to write draft introduction. Realise how in the past research into MS has been dominated by looking for pathological cause and effect relationships. No one looking for how cope. MS patients never consulted. Shows me the importance of assumptions behind research.
- 9.2.96 Receive a supportive letter from Phil.
- 10.2.97 Received a letter from the neurologist about two more people interested in the research.
- 13.2.97 First interview- went on for nearly two hours - It was a good interview and the woman talked in depth about her experience. She had received quite a bad deal from the health service. It felt difficult being a researcher, listening to experience and problems but not offering any help. Suggest will try and arrange an appointment to see a psychologist for her relationship difficulties.

- 15-16.2.97 Spent the weekend typing up the first interview. Taking a lot longer than I anticipated. Wondering how I am going to type up all the interviews in my spare time and how am I going to analyse all the data..
- 19.2/97 The vice chairwoman from the MS Society rang. The committee have agreed in principle to me approaching some of their members. She and the welfare secretary would like to meet with me to discuss the project further.
- 20.2.97 am Second interview. This was completely different to last one. The man was not so expansive and I had to work hard to keep the interview going. However, there was plenty of insights and a feeling of hopelessness.
p.m. Meet with Brian. Debrief about the interviews. I had not realised how much they would affect me. Feeling impotent as I can not do anything to help. Is this how medical services feel?
- 22-23.2.97 Finish typing first interview. 26 pages of text to analyse!
- 27.2.97 Met with the vice chair and welfare secretary from the MS Society. Feel the need to impress. They were very nice and felt that they could help. Agreed to pass on some information sheets.
- 7.3.97 Finish typing the first two interviews. Send copies to supervisors and back to participants.
- 14.2.97 Met with Brian to discuss interviews. He felt they went well and we discuss them in some depth. Start to look at the idea of positioning. How participant's see me. Also the tension of positioning myself with the medical services who are distrusted by participants at the same time as trying to position myself on the participants side.
- 24.3.97 Have to concentrate on the essay. But I have arranged two interviews this week. Meet with one man who is on the MS committee. A good interview with plenty of information. Yet more bad experiences with the medical services.
- 25.3.97 Met with another man on the MS committee. Comes across as a real fighter (a theme which everybody has shown so far). He feels tired by the end of the interview. I hope it hasn't been too long.
- 26.3.97 Rang the welfare secretary and asked her if she could give another 5 information sheets out. Would like to interview participants with greater disability and some with the more benign form of the disease.
- 30.3.97 Essay handed in and time for a short holiday.
- 7.4.97 Met with a woman who was diagnosed seven years ago and is now quite disabled. She had two young children and life should be very difficult for her. However she has discovered a herbalist who has made her feel a lot better and she has hope for the future.

- 8.4.97 am Met with a woman who was very disabled. She did not talk at length. Feel quite upset after this interview.
- p.m. Another interview in the afternoon.
- 9.4.97 am- Met with a man who is the most disabled person I have met so far. He couldn't use his arms, legs and his voice was starting to go. He was full of life and joked throughout the interview. I only feel sad after I have left and think about his situation.
- p.m. Another interview.
- 10.4.97 Met with an interesting woman who has had MS for forty years. Attitudes to her in the past were appalling. Drs gave up, she was not told diagnosis until 10 years after it was made. The interview was not quite as I expected as she had a benign form of MS and she talked about a number of other things. Made me think how diverse this disease is.
- 11.4.97 Typing interviews up. It has been an busy week interviewing six people . Feel emotionally exhausted.
- 12-13.4.97. Spend the weekend typing the first five interviews. Is this ever going to end.
- 14.4.97 Still typing the fifth interview. Frustrating because I want to get on with the analysis.
- 15.4.97 Start the first phase of the analysis. Decide to analyse the first five interviews to provide a basic account. Then add the next five interviews to the account. Refer to Henwood and Pigeon again to remind me of the approach. Devise my own steps based on their ideas.
- 1 prepare interviews by numbering.
 - 2 initial code line by line into concepts.
 - 3 sort concepts into categories and transfer to index cards. (put all examples of particular concepts onto one card)
 - 4 start to define concepts..
- Start this process... easier than I thought in terms of coding but takes a long time and is very tiring. First interview results in 140 coded bits of information Do the second interview in the afternoon. End up with 77 coded bits of information..
- 16.4.97 Code two more interviews. 122 coded bits for the third and a 103 for the forth. Lots of repetition. spent evening typing next five interviews..feel immersed in the data. Starting to understand but how am I going to organise my ideas?
- 17.4.97 Last interview in phase one, results in 116 coded bits.

p.m. meet with Brian. very useful meeting again. Debrief about interviews- the ones with the more disabled participants were very difficult. Discuss whether to do a reliability check.. But with who, another psychologist? someone with MS? a medical doctor? Also in grounded theory much of the coding requires interpretation.

18.4.97 Read about cognitive approaches to coping. It feels very limited as coping with discrete events rather than a whole lifestyle with chronic illness.

20-21.4.97 Typing all weekend.

23.4.97 Start to transfer codes onto index cards. Sort the coded bits of information onto 40 cards

28.4.97 New placement. Difficult to raise the energy to start again.

1.5.97 Tried to arrange an appointment to see a psychologist for one participant. It has to go through the GP fundholder as that is who the contract is with. Experience first hand the difficulty of accessing services. Finish transferring coded bits onto index cards. End up with 63 cards.

8.5.97 Return to draft introduction and make some progress but it is so difficult having to juggle everything at once..

9.5.97 Need to structure a theoretical account from my index cards. Decide to spread all the cards out on the floor. Some fit in a temporal sequence, some go into clusters, others stand alone. Revisit the research aims and start to organise into themes.

15.5.97 Job interview. Could do without it at this point in time.

17.5.97 Start to define themes. Some categories split into two others are merged. Write a definition and add participants quotes. This bit seems a leap from analysis to interpretation. Send off ideas to Brian and Phil.

23.5.97 Meet with Brian. Get good feedback on ideas so far. We talk about the similarities and differences with his work on HIV and how to represent the positioning stuff.

24.5.97 Letter from Phil- basically fine, some suggestions.

5.6.97 Have arranged four more interviews to test out the emerging theoretical account. Interview a woman who has had MS for a long while but lost the use of her legs last year. This combined with living in a flat with steps so she can't get out and her general poverty makes it a difficult interview. She had suffered severe mental health problems in the past. My first experience of meeting someone who has not coped well in the past.

6.6.97 Interview another man whose wife left him last year.

- 12.6.97 Interview another woman.
- 17.6.97 Last interview. Difficult again because of the difficulties she has had with medics. She is very angry with their lack of sensitivity and support. Also sense of loss. She fell over as she saw me to the door. Her husband was there also luckily.. I experience first hand the embarrassment of the situation. These last few interviews have been the hardest. I think there is a real limit to how far this research can go without a service to offer people.
- 18.6.97 Feeling panicky .. running out of time with still a lot to do.. working all hours
working a lot on the results- having to cut out a lot because of word limit.
- 24.6.97 Receive comments on draft introduction. Seems fine just needs more structure.
- 26.4.97 Send off report for respondent validation. Later than I wanted but I could not do it until the results section was done. Hope participants like it.
- 2.7.97 Send off draft method section. Feeling ill. I have been working 7 days a week for the past two months and feel exhausted.
- 10.7.97 Feedback on the results section. Need to rethink the structure.
- 12.7.97 Receive feedback from the respondent validation and from the psychologist. Lots of nice comments. Makes the research worthwhile. Feel relief as this has been such a solitary experience. Nice to see that others agree.
- 14.7.97 Feedback from the welfare secretary. Glad she agreed as she is working at the coalface. Draft discussion to Brian
- 15.7.97 Been working all hours for past three weeks. Finish typing up extracts from the diary, can not believe how long I have been thinking and working on this dissertation.
I Still feel exhausted but I also still feel positive about the research which I am surprised at. In the past I haven't felt positive at this stage. Although this approach has limitations I think I have learnt a lot both about MS and about research in general.

APPENDIX 2

INFORMATION SHEET FOR PARTICIPANTS

A RESEARCH PROJECT EXAMINING INDIVIDUAL EXPERIENCES OF LIVING WITH MULTIPLE SCLEROSIS.

I am writing to ask you if you would like to take part in a study looking at the experience of having Multiple Sclerosis.

Title of project

A study exploring the personal experiences of people with multiple sclerosis

Ethics

This research has been granted ethical approval from _____ Committee.

Outline

It is very important to understand at first hand how Multiple Sclerosis affects people's lives. At present, however, this experience is still not well understood. There has not been much research actually asking individuals with multiple sclerosis about what their illness means to them and what their experiences have been.

The main aims of this research are to understand how individuals manage and cope with MS, the social factors that help or hinder this and individual's experiences of services. I hope that the results of the research will help others understand the difficulties of living with MS and be used to develop services to help people with these difficulties.

What would be expected of you?

Information for the study will be gathered through a face to face interview with me Jonathan Reed, Psychologist in Clinical Training. It is expected that the interview would last up to an hour and a half. The interview can take place either at your home

or at a local office and at a time that is mutually convenient. With your consent the interview will be recorded on tape. You will be able at any point to ask me to stop the tape. The tape will then be transcribed and a copy will be sent to you to check that it is accurate. The tape will be destroyed after this. After the study is completed a summary report of the research will be available for everyone taking part in the study.

Confidentiality and anonymity

The information from the study will be strictly confidential. Once the research is written up any information identifying you will be disguised or removed so that no one would be able to tell that you took part in the research.

YOU WILL HAVE THE RIGHT TO WITHDRAW FROM THE STUDY AT ANY STAGE.

Thank you for taking time to read this information

If you are interested in taking part in this research please fill in your name, address and telephone number on the form over the page and send it to me in the Freepost envelope provided. I will then get in contact with you to arrange a mutually convenient time and place for the interview.

If you have any questions or would like any more information please do not hesitate to contact me after 7.00 p.m. on or during work hours on Monday, Tuesday or Wednesday on .

Please see next page for details of how to participate in this study.

**Paginated
blank pages
are scanned
as found in
original thesis**

**No information
is missing**

APPENDIX 3
CONTACT FORM

Please fill out this form and return it in the FREEPOST envelope provided

A study exploring the personal experiences of people with Multiple Sclerosis.

Investigator: Jonathan Reed

Psychology Department

Salomons Centre

Broomhill Road

Southborough

Tunbridge Wells

Kent

TN3 OTG

Please fill in the following details

Name _____

Address _____

Telephone Number _____

I am interested/ am not interested* in taking part in the study.

* please delete as appropriate.

Note: If you send this slip back you can still withdraw from the study at anytime if you wish. Deciding not to take part in the study will not affect the care you receive in any way.

APPENDIX 4

Letter to neuropsychologist Re recruitment procedure

Dear Dr

In follow up to our telephone conversation I enclose copies of my ethics submission, my dissertation proposal, copy of the letter granting ethical approval and 20 information sheets and envelopes for patients with MS.

As we discussed over the phone I would be very grateful if you and/or Dr could hand out the information sheets to your patients with MS. They will then be required to send me back a contact form in the SAE envelopes provided. I am going to wait and see what response I get from this initial batch of contact forms and providing it is OK with you and Dr I will send you some more sheets and envelopes later if necessary. I am also going to try to obtain some participants from the local MS society. In total I want to interview around 20 people with MS.

The exam board asked me to specify whether the patients I am going to interview have a diagnosis of definite MS. I have said provisionally that they will, however, could you ask Dr whether he gives this diagnosis to his patients or whether they are likely to have been given this diagnosis by others. If this is the case could the information sheets only go to patients with a definite diagnosis of MS. Also as we discussed on the phone could you both avoid giving the information sheets to people with significant cognitive impairment.

As we discussed when I initially spoke to you, for the purposes of ethical committee, as a safeguard, I said that I would speak to you if anyone was seriously distressed some time after the interview. I hope that this is still OK, however, I think the chances of this happening will be extremely unlikely.

I hope all this makes sense, however, please do not hesitate to contact me if you want to discuss any aspect of the study further. I will be in contact soon to check that everything is OK.

When the study is complete I can send you and Dr a summary report giving full details of my findings. Also I would be happy to meet with you and Dr to discuss the study in more detail if you wanted to.

Once again thank you very much for helping me with this study.

APPENDIX 5

Letter to MS Society Re recruitment

Address

Tel No (Evenings and Thursdays)

Work number (Mon, Tues, Wed)
Ext

31st January 97

Dear Mrs

Thank you for your time the other day when we spoke on the phone. As we agreed I am writing with the details of my research project so that the Multiple Sclerosis Society committee can discuss whether individuals from the society would like to participate in the research.

The aims of the research project are to examine the views and experiences of people who have Multiple Sclerosis. The project will be written up as part of my doctoral degree in clinical psychology. I enclose a copy of the information sheet giving details of the research and what would be required of individuals taking part (Enclosure 1). These sheets would be sent to anyone interested in taking part in the research. After reading the sheet if they were still interested they would then be required to send back the contact form in a stamped addressed envelope and I would then contact them to arrange an interview. The interview would cover the individual's experiences of living with Multiple Sclerosis from their diagnosis onwards, including their experience of health and support services. The interview should last no longer than one and half hours and would be recorded on tape. When the research is written up individuals who took part will remain anonymous and the interview tapes will be destroyed. Individuals would also be able to withdraw from the study at any time.

The reason I am undertaking this research is that while there is a lot of research looking at the psychological and medical effects of Multiple Sclerosis, very little research has actually asked people with Multiple Sclerosis about their views and experiences. I have experience working in rehabilitation services for people with neurological illnesses and this has made me aware of the difficulties people can face when living with illnesses such as Multiple Sclerosis. I hope that the research can be used to influence service provision for people with Multiple Sclerosis. I also hope that it will help professionals better understand the hopes and concerns of people with Multiple Sclerosis. I also believe that an analysis of individual's experiences of living

with Multiple Sclerosis will be helpful to other people who have been recently diagnosed with the disease.

The project has been scrutinised ethically and has full ethical approval from the Ethics Committee. I enclose a copy of the letter confirming this (see Enclosure 2). Dr Consultant Neurologist for the district is also aware of the research and is helping me to recruit participants for the study. I would also be very happy to discuss any aspect of the research with the local Multiple Sclerosis Society committee or any representative from the committee.

If the committee feels that individuals in the Society would be interested in taking part I would need to distribute the information sheets, contact forms and stamped addressed envelopes to them. I could do this by either sending a number of copies of these forms to the society to distribute or alternatively if the society could give me the names and addresses of anyone interested I could send them the details direct.

I would also very much like to talk to someone from the committee who would be willing to advise and give their views on the interview schedule for the project. Whilst I have a good familiarity with the medical and psychological literature on Multiple Sclerosis I am very keen to hear the views of people with direct experience of helping people with the illness.

After the research is completed in July 1997 I would be very happy to send a copy of the report of the research to the Society and to discuss the findings of the research with the committee.

I hope that this letter provides all the information that you require, however, please do not hesitate to contact me if you have any further queries.

I look forward to hearing from you in due course.

yours sincerely

Jonathan Reed

Psychologist in Clinical Training

APPENDIX 6

INTERVIEW GUIDE (NO 1)

Introduction (to be read out)

Thank you for agreeing to take part in this interview. As was mentioned on the information sheet that you received, this research is an attempt to understand what your experiences of living with MS have been. My interest in this area came from working with people with MS and realising what a difficult and complex disease it could be to live with. I have also tried to think about what would be the best ways to help people with this. When I looked at the research in this area I found that very few people have actually asked people with MS for their views and experiences.

I believe that this research will be useful in several ways. I hope that it can be used to develop services by helping health care professionals understand the concerns of people with MS. I also hope it will be useful for other people with MS.

Before we start the interview I would like you to read and sign this consent form providing you are happy to continue. (Hand over form).

I would like to also remind you that you can stop this interview at any time and withdraw and that this will not affect any service you receive in any way. Also I will stop the tape at any point if you want me to.

Interview guide

(Note: The following is just a guide to the areas I want to cover.)

A Initial information

To start with would you mind telling me something about your personal circumstances?

Areas to cover

Age.

Family circumstances.

Domestic situation.

Employment past/present.

Time since diagnosis.

Level of disability

General health and health history

B Experience prior to diagnosis

Could you tell me about when you first started to realise that you might be ill ?

Areas to cover

First recognition of symptoms.

Meaning at the time.

Role of friends and family in reassurance/ seeking medical help.

C Diagnosis

(If it has not come up from previous section). Could you tell me how the diagnosis was made?

Areas to cover

How helpful was the process of diagnosis?

How much information was given?

How long did it take to sink in?

D Progress since

Could you tell me about the progress of the disease since then?

Areas to cover

Meanings of different experiences?

Feelings associated with these experiences?

How coped with different experiences?

Role of other people? Family, friends?

E Role of services

(If not already raised). Have you had any experience of health services since being diagnosed ?

Could you tell me about these?

Areas to cover

Positive and negative experiences of services

Views on service development

Hopes/ expectations versus reality of medical/ support services.

F Ending

What do you feel you have learnt from your experience of having MS?

Are there aspects of MS which the interview ought to have covered but has not and if so can you tell me about these?

DEBRIEFING

Thank you for participating in this interview.

I would like to tell you about the research. I am (have) interviewing (ed) a number of people with MS and then analysing these interviews. I will be looking for common themes and differences between people. From this I am hoping to build an account of the difficulties people with MS encounter, the ways they cope with these and the role of other people in this. I am also examining individual's experiences of services and the extent to which these facilitate or hinder coping.

1) Would you like to ask me anything about this?

(CHECK)

2) How are you feeling now having finished this interview ?

[If Problems a) Talk about these

b) Give contact number if necessary

c) Ask participant if he/she would like me to talk with Dr about situation]

3) Were there any parts of the interview that were particularly difficult ?

I would like to send you a transcript of the interview so that you can check it to see that it is an accurate record of the interview. I will send you a SAE so that you can send me any comments about it. Is that OK? (Record Y/N)

I would also like to send you a summary copy of my findings when the research is completed next August. Would you like me to do that. (Record Y/N).

If you have any queries or worries later please phone me on (Ext). I work there Monday Tuesday and Wednesday. If I am not there please leave a message and I will get back to you as soon as possible.

Have you got any questions you would like to ask ?

Thank you once again for your participation.

MID SUSSEX

NATIONAL HEALTH SERVICE TRUST

The Princess Royal Hospital Haywards Heath West Sussex RH16 4EX TELEPHONE: (01444) 441881

Our Ref: JMB/apc

Date: 16 October 1996

Mr Jonathan Reed
Psychologist in Clinical Training
South Thames Clinical Psychology Training Scheme
Davaid Salomons Centre
Southborough
Tunbridge Wells, Kent.

Dear Mr Reed,

**Re: STUDY EXPLORING THE PERSONAL AND SOCIAL
EXPERIENCE OF LIVING WITH MULTIPLE SCLEROSIS**

This Research project was given ethical approval at the Meeting of the Committee on 3 October 1996.

I have to remind you that if this work involves the use of Mid Sussex NHS Trust facilities the approval of the Trust Board must be obtained before this research can begin. The best way to expedite this is to let David Long have a copy of the protocol.

Other NHS Trusts may well have similar requirements and it would be advisable to check if their premises or personnel are involved.

For those projects involving the Mid Sussex NHS Trust there is also a requirement that the prior agreement of support services eg pathology, imaging, pharmacy is obtained before the work begins.

Yours sincerely,



J M Berry
CHAIRMAN

EAST UNIT RESEARCH ETHICS COMMITTEE

APPENDIX 8

CONSENT FORM

Title: A study of the personal and social experiences of individuals with multiple sclerosis

Principle Investigator: Jonathan Reed

Psychologist in Clinical Training

I (name) _____ agree to take part in this investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw from the investigation at any stage without necessarily giving a reason for doing so and that this will in no way affect the care that I receive as a patient. I understand that the interview will be recorded on tape and that I can at any time ask for the tape to be turned off.

This research has been approved by _____ . From time to time the committee will contact some research subjects to check that the research is being done in an ethically correct way. By agreeing to take part in this research you also agree that the person doing the research can tell the ethical committee your name and address so that they can contact you but you need not answer their questions if you do not want to.

Signed _____ Date _____

APPENDIX 9

Extract of interview with an example of coding.

Interview No 1

Can I take you back a bit to when your first symptoms occurred. Could you pinpoint that or ..?

It's difficult. Yes I think it was when we went on holiday. We did a coach trip to Switzerland. Um I never travelled. I'm not a happy traveller. I don't like travelling in cars, but I mean we'd been on this coach trip and we'd gone to Switzerland, and I was out walking one day. We walked, we'd walked a lot- we're great walkers- and um I was out walking, walking along the seafront and I thought I don't feel quite right here. I felt as if I was walking on cotton wool or rubber, you know, a bouncy sort of rubber. I can't really explain but it's as if I was bouncing along. And um that sort of came and went and I thought well something's causing it. But there were no other signs and I didn't sort of worry about it, and that must have been a good 18 months before the signs started getting... That bouncy walk started getting more obvious. But I still choose to ignore it I suppose.

Did you talk to your husband at all about it or any friends ?

Yes..... Yes I spoke to him. I sort of said I've got this sort of funny walk, and he I suppose, he felt that as I wasn't too concerned about it he didn't feel too concerned about it either. I think he,..... he sort thought if and when something needs doing she'll go to the doctor and get it seen to. I suppose I just put it off and put it off. because it was inconvenient.

So you had the first experience which subsided... when did it come back again?

Um well I suppose it was soon after we'd moved and we'd been through the move and I sort of got very tired and so on. And um it really came quickly then. um within a month um it started um the bouncy walk sort of got worse. And then I started to go numb. Strangely enough I think it was my left leg that went numb to begin with. It was not completely numb, you know, when you've been asleep and you've laid on your arm and you've woken up and its sort of tingly and it s just coming back to life as it were. And you feel, you know, that there is something not quite right. And then um it affected both legs and came right up to my waist. And then to my chest and shoulders. And this must have been about June, no it must have been April, late April.

And what was going through your mind at that time .. What did you do?.

I don't think I was sort of frightened or anything like that I was sort of, I suppose I wondered what it was. But I didn't immediately think of any sort of awful illness. I felt it was going to be some transient thing that would go away. I mean, I suppose I'm a bit like that about illness anyway. It's there but um it will be gone in a few days. I suppose that's the way I felt about it really. um I suppose um when my husband realised that I was staggering around and um had trouble getting up stairs, I think he said to me 'don't you think you sort of better go and I get it seen to?' And I realised that I can't go on like this because it was interfering with my life and stopping me from doing things, and that I should do something about it. But I probably should have done something about it. But I'm afraid its one of one of my faults.

Did anybody else know at this time? did you talk to anyone else about what was happening or ?

um.. Not particularly, though I Mean my parents live down in and we used to visit them. They had moved and we were seeing quite a lot of them and they realised that I was having trouble walking, and they sort of asked questions well what about your leg. And I'd say 'its gone a bit numb and feels a bit peculiar' and my mum, of course, she was always one to going rushing to medical books, obviously looked it all up. And of course, as soon as I knew that it was MS and I was telling people and she said 'well of course we knew was MS because I've looked it up in book'. She read it all. She obviously knew that I'd got it. So everybody else knew. But I threw all my medical books away years ago . I haven't got a medical book in the house. I always think there are more trouble that they are worth. So I didn't go rushing to any books. But my mother did. But yes, although I did say, she knew there was something wrong with me and I think she put two and two together. And when I was diagnosed I hadn't got a clue what was wrong with me really.

Had you heard of it before?

No, all right, I heard somebody say, you know, so and so's got Multiple Sclerosis but I hadn't a clue what it was about, or what it involved, um and so I had a lot of finding out to do.

Codes

- 1.5.3-14. First recognition of symptoms,-pre-diagnosis.
- 1.5.8-9 Experience of strange bodily sensations.-pre-diagnosis.
- 1.5.12-13. Ignoring initial symptoms- ?denial.
- 1.5.14-17. Role of partner in checking out symptoms.-pre-diagnosis.
- 1.5.17-18. Ambivalence about seeking medical help- pre-diagnosis.
- 1.6.1-9. Significant attack-pre-diagnosis.
- 1.6.4-9. Experience of strange bodily sensations.- pre-diagnosis.
- 1.6.7-9. Feeling of engulfment due to symptoms.
- 1.6.10-12. Attribution of attack to transient illness- pre-diagnosis.
- 1.6.11-14. Denial- pre-diagnosis.
- 1.6.15-16. Partner suggests seeking medical advice- pre-diagnosis..
- 1.6.15-19. No longer possible to ignore the symptoms- pre-diagnosis.
- 1.6.16-18. Symptoms start to impair everyday life-pre-diagnosis.
- 1.6.18-19. Conflict about avoidance.
- 1.7.1-4. Parents notice something wrong.
- 1.7.5-8 Mother taking an active stance and informing others.
- 1.7.8-10. Participant avoiding medical information from books.
- 1.7.12-13. Diagnosis has little meaning.
- 1.7.7-8 and 1.7. 11-12. Mother worked out what was wrong before diagnosis.
- 1.7.14-16. Diagnosis has little meaning.

APPENDIX 10

Example of an index card.

Card 20 Fighting MS

Ref no	Summary
1.8.11-12.	MS not going to ruin my life
1.18.2-3.	Trying to avoid using a wheelchair.
1.21.22-1.22.1.	Not getting a stairlift as become reliant.
2.14.14-17.	Keep exercising or MS will take over.
3.22.8-10.	Crawling out of bed in order to shave etc.
4.14.19-22.	Do not use walking aids unless absolutely necessary.
4.14 .26-28.	Reject stairlift because come to rely on it.
5.2.4-7.	Adopt a fighting stance after diagnosis.
5,14,12-13.	Defying expectation to go into a wheelchair.
5.19.26-20.	Fighting dependence.

APPENDIX 11

Initial categories.

- 1 Precipitating attack before diagnosis.
2. Decision to seek medical help
3. Referral to specialist service
4. Uncertainty after diagnosis- MS has little meaning.
5. Making sense of symptoms.
6. Communication of diagnosis.
7. Initial reaction to diagnosis.
8. Relatives told about diagnosis first.
9. Rationalising medical behaviour.
10. First symptoms in retrospect.
11. Ignoring symptoms.
12. Role of partner.
13. Sudden changes.
- 14 Interaction with enduring characteristics.
15. Role of parents/ siblings.
16. Not understanding MS
17. Role of MS society.
18. Treatment.
19. Acknowledging MS.
- 20 Fighting MS.
21. Worse case scenario.

22. MS fades into background.
23. Gradual deterioration.
24. Participants search for triggers for MS/ relapse.
25. The use and meaning of physical aids.
26. Patterns of remission and relapse.
27. Emotional effects.
28. Alternative treatments.
29. Role of children.
30. Role of friends/ strangers.
31. Seeking information.
32. The need for planning because of MS.
33. Positive medical experiences.
34. Negative medical experiences.
35. Disillusion with medicine.
36. Experience of other NHS services.
37. Experiences of social services.
38. Public profile of MS.
39. Decision to change lifestyle.
40. Service needs
41. Meaning of referral to specialist services.
42. Waiting for results.
43. Home helps.
44. Use of activities to mark deterioration.
45. Isolation.

46. Physical symptoms.
47. Fear of deterioration.
48. Loss of independence.
49. Learning experiences.
50. Coping.
51. comparison with other: re help seeking.
52. Trying to make sense of symptoms.
53. Adapting to MS: the use of strategies.
54. Daily fluctuations.
55. Moving to a world of illness.
56. learning from other people with MS.
57. Home environment.
58. Feeling out of control.
59. Distress at symptoms.
60. First attack after diagnosis.
61. Impact of life events and MS.
62. Respite services.
63. Knowing when relapses are coming.

APPENDIX 12

Semi structured interview schedule (NO 2)

Introduction (to be read out)

Thank you for agreeing to take part in this interview. As was mentioned on the information sheet that you received, this research is an attempt to understand what your experiences of living with MS have been. My interest in this area came from working with people with MS and realising what a difficult and complex disease it could be to live with. I have also tried to think about what would be the best ways to help people with this. When I looked at the research in this area I found that very few people have actually asked people with MS for their views and experiences.

I believe that this research will be useful in several ways. I hope that it can be used to develop services by helping health care professionals understand the concerns of people with MS. I also hope it will be useful for other people with MS.

Before we start the interview I would like you to read and sign this consent form providing you are happy to continue. (Hand over form).

I would like to also remind you that you can stop this interview at any time and withdraw and that this will not affect any service you receive in any way. Also I will stop the tape at any point if you want me to.

Interview guide

(Note: The following is just a guide to the areas I want to cover.)

To start with would you mind telling me something about your personal circumstances?

(Age, Marital status, Former occupation, Time since diagnosis)

1 Before you were diagnosed did you have any symptoms?
Could you tell me about these?

2 Could you tell me how the diagnosis was given?
How did you feel after this?

3 What happened after diagnosis?
(information, experience) What were your ideas about MS then?

4 Has your MS progressed since then?
How did you feel at different times?

How cope at different times?

Do you think about your MS a lot of the time or not?

5 Do you think you have accepted your MS?

6 How has the MS affected your relations with your family?

7 Do people react any differently to you because you have MS? In what ways?

Does this worry you?

Do you talk about your MS with others very much? To others with MS?

8 How much contact have you had with Dr's since diagnosis? Has this been helpful?

Have you had contact with social services? expand

Do you find the MS society helpful? what do they provide?

9 What do you feel you have learnt from your experience of having MS?

10 Is there anything that we have not covered in the interview which you feel we should have covered?

DEBRIEFING

Thank you for participating in this interview.

I would like to tell you about the research. I am have interviewed a number of people with MS and then analysing these interviews. I will be looking for common themes and differences between people. From this I am hoping to build an account of the difficulties people with MS encounter, the ways they cope with these and the role of other people in this. I am also examining individual's experiences of services and the extent to which these facilitate or hinder coping.

1) Would you like to ask me anything about this?

(CHECK)

2) How are you feeling now having finished this interview?

[If Problems a) Talk about these

b) Give contact number if necessary

c) Ask participant if he/she would like me to talk with Dr about situation]

3) Were there any parts of the interview that were particularly difficult?

I would like to send you a transcript of the interview so that you can check it to see that it is an accurate record of the interview. I will send you a SAE so that you can send me any comments about it. Is that OK? (Record Y/N)

I would also like to send you a summary copy of my findings when the research is completed next August. Would you like me to do that. (Record Y/N).

If you have any queries or worries later please phone me on (Ext). I work there Monday Tuesday and Wednesday. If I am not there please leave a message and I will get back to you as soon as possible.

Have you got any questions you would like to ask ?

Thank you once again for your participation.

APPENDIX 13

Summary Report after Initial Analysis.

A theoretical account of the process of psychological adjustment to MS based on accounts by individuals living with the disease.

Introduction

Although a great deal of research has been undertaken examining the psychological aspects of Multiple Sclerosis little research has been undertaken in which individuals are asked about their experiences of living with MS.

The aims of this research were to examine how individuals with MS describe their experiences of living with the disease and then to develop a theoretical account of the process of adjustment to MS from these accounts. Fourteen individuals with MS were interviewed about their experiences of living with the disease since before diagnosis. The interviews were then typed up and analysed. The results show that while there was a great deal of individual variation in experience the analysis revealed six common themes. These are described below.

Results.

Theme 1 Adjustment to MS is not about adjusting to one thing, instead it consists of a number of distinct but connected adjustment processes which differ depending on individual circumstances.

The adjustment process includes.

a) Adjusting initially to changes in bodily sensations prior to diagnosis.

Most individuals in the study could trace back symptoms for many years before diagnosis. These sensations could be quite strange and included loss of control of limbs, inexplicable falls, people feeling that their legs had gone numb, extreme dizziness and one woman said she felt 'like I was walking on cotton or rubber'. At first individuals tended to dismiss these sensations believing that they were caused by overwork, tiredness or as just part of the individual's makeup. However, at some point they made an adjustment to believing that the sensations may be more serious. This usually occurred when the sensations began to significantly affect the person's life or when they suffered a sudden dramatic attack of symptoms. This led to individuals being admitted to hospital or seeing their GP and eventually receiving a diagnosis of MS.

b) Adjusting to diagnosis.

Everybody in the study was given a definite diagnosis of MS. How individuals reacted to this depended in part on how the diagnosis was communicated and in part to what the diagnosis meant to individuals.

In some cases the individual's partner was the first person to be told about the diagnosis. The individuals with MS were sometimes not given the diagnosis for weeks after. This resulted in tension in some families as one partner had to keep the diagnosis secret from the other. Most people felt very angry about this. When individuals were given the diagnosis some were given the news very directly with little preparation. Individual reactions to this approach included shock, anger, feeling very upset and sometimes anxious. Giving the diagnosis in this way also seemed to have had a negative effect on their relationship with their doctor for a long while after. Some people found it more helpful to be told in such a direct way. In other cases the diagnosis was communicated more sensitively and with some preparation and this tended to lead to less distressing reactions. Many people seemed relieved to know what was wrong with them.

Individual reactions to diagnosis also depended on the meaning of the diagnosis. Some people had some idea of what MS was at diagnosis (see Theme Four below for fuller discussion of this). These individuals tended to feel more distressed initially. In

contrast a lot of individuals did not know what MS was and therefore initially the diagnosis had little meaning to them and they did not feel very distressed.

c) Minimal need for adjustment.

Some individuals found they had few if any symptoms for years after the diagnosis. For these individuals there was little to adjust to. They had been given a diagnosis of MS with the threat of potential symptoms but when nothing happened they got on with everyday life and the MS faded into the background.

d) Need for gradual adjustment.

For many people in the study, MS was characterised by periods of relapse when the symptoms occur for a brief period and periods of remission where symptoms subsided. In these cases MS became an interference in everyday life. Attacks meant that individuals couldn't do much for a while or that they had to take time off work. However, over time these attacks also resulted in individuals gradually becoming more disabled. This called for a more gradual adjustment process as individuals gradually became aware of the ways in which their MS was affecting them personally. On a day to day basis individuals found it difficult to recognise that they were becoming more disabled. Some people only recognised this when they could no longer do certain activities that they used to be able to do, such as jobs around the house. Also some people felt that certain activities such as walking to the bank each week acted as a check on how disabled they were.

d) Adjustment to sudden major change.

For many individuals there were some times when they had to adjust to a sudden major change. This may be because they reached a point where they had to give up work, or suddenly go into a wheelchair (See next section (e)) or had to give up driving. In these cases individuals had to adjust their view of their position in the world rapidly. This can result in shock reaction. In addition some individuals had MS that progressed rapidly without breaks. Again there was a need to adjust quickly to changing events. Individuals in this position had to develop good coping strategies to deal with this.

e) Adjustment to physical disability.

Not everyone in the study had to use a walking aid. But for those that did additional adjustment was required. Using a stick or wheelchair meant that their disability became more visible to others which required additional social adjustment (See Theme 3 below). Some people in the study used sticks and chairs only when they were forced to do so because they couldn't get around without them. Other people found they used aids to make life easier when going out. Some individuals used mental strategies such as trying to look as well as possible while using a chair so that other people would not feel sorry for them. Also some individuals found initially that they felt embarrassed by going out but then found that they felt better when they had confronted their fears.

Theme 2 Adjustment to MS is often an active process rather than just a reaction to events.

a) Making sense of uncertainty.

After diagnosis individuals do not know how their MS will progress. Analysis of the interviews suggested that individuals used a variety of methods to understand what was happening to them. Some individuals sought out books and leaflets to give them information. Others obtained information from the MS society. Few people received information from the health service. Individuals also tried to understand what was happening to them from their experiences of symptoms. Some individuals tried to work out what bodily sensations could be attributed to the MS and which could not. Other individuals tried to work out what triggered their relapses (explanations included the immune system being low and tetanus injections). Other individuals were able to detect changes in their bodies when a relapse was about to occur and were then able to prepare by resting.

b) A fighting attitude.

Many individuals in the study developed a 'fighting' attitude in order to prevent the MS taking over. As well as a general attitude, strategies included keeping as active as possible, not using aids and adaptations until absolutely necessary and maintaining as much independence as possible. This was also seen in strategies that individuals used to maintain roles and activities. For example one man took a folding seat with him when he went into town so that he could rest when he was tired. Another woman sat on her stairlift going down one step at a time in order to clean the stairs.

Theme 3: Accepting the MS.

After living with MS for a while many individuals felt that they had reached an accepted of their MS. Acceptance in this sense included taking the MS into consideration when undertaking activities, having to include the MS in short and long term plans and accepting limitations. Not being upset when talking about the MS and realising that it was not going to go away. This occurred at different times for different individuals. There continued to be a tension between acceptance and fighting the disease. Acceptance did not mean giving up, instead it was about the recognition that one had MS and that this meant some limitations and required some planning but also that it was necessary to fight to maintain roles, activities and independence.

Theme 4 Adjusting to MS is not just an individual process it involves social adjustment.

Family adjustment

The study also showed that many individuals were part of a couple or a family and that adjustment was required by the unit as a whole. Partners were often present from the diagnosis onwards and shared the ups and downs of the MS process. Also some partners had to adopt new roles for example by helping to care for the person with MS. Not being able to talk about their concerns or being able to adjust to new roles led to problems for some couples.

MS also affected the rest of the family. This differed depending at what stage the family were at in terms of the family life cycle. Some individuals had grown-up children where the effects of MS did not seem so great, whereas others had young

children where talking about the diagnosis and prognosis was difficult. A similar process seemed to happen with parents. Some individuals did not want to worry their elderly parents and did not talk about their MS with them much. In general families differed in the extent to which they talked about MS with some families finding it very difficult to talk about the disease and its effects.

Social adjustment

Another theme that emerged from the interviews was the difficulty some people found in talking to others about MS. Most individuals felt that other people did not understand what MS was and what it meant. Individuals found it difficult to explain to others. Also individuals in the interviews did not want to be treated differently because they had MS. This had to be negotiated and in some cases people felt they were treated differently especially if they had to use a wheelchair. These difficulties led to some people feeling quite isolated.

Theme 5 Adjustment in comparison with the worse scenario image/ belief about MS.

Many people in the study developed an idea early on of what the worse case scenario with MS would be. This could be an image from the media, from a famous person who had MS such as Jacqueline Dupre, from a meeting with people who are very disabled or from a relative who suffered badly from MS. Often this image was based on someone in a wheelchair who was very dependent/ disabled. Individuals sometimes coped initially by thinking that this wouldn't happen to them. This image/ belief also seemed to be used by individuals at different times to monitor how their MS was progressing. Many people coped by saying that they could be a lot worse in terms of MS. Even individuals who were significantly disabled and dependent could think of worse scenarios.

This comparison process may have influenced a number of people who either didn't want to meet other people with MS or if they did meet did not want to talk about MS in any detail. Some suggested that this may have been because it is difficult to talk about and difficult to cope with people more disabled than themselves. When individuals did

meet with others who were disabled or when they talked about their symptoms they tended to find it very helpful. Individuals felt they learnt from others and felt a sense of belonging with others 'in the same boat'.

Theme 6: Individuals go through a process of service use.

In the study the first contact that many individuals had with specialist health services was at the time of diagnosis. This normally involved specialist procedures and equipment such as brain scans and suggested that medical understanding of MS was quite advanced. Also early on many individuals found they benefited from specific treatments to relieve symptoms such as steroid treatment. However, as time progressed many individuals tended to become more disillusioned with the medical approach. They felt it did not have much to offer. Some individuals saw different doctors on each hospital visit, they found there was not much time to talk and the service felt impersonal at times.

In response some individuals turned to alternative approaches such as herbal medicine or the use of cannabis. Also when individuals became more disabled, help with everyday living became more important. In this situation some people found that social services were more helpful to them, providing adaptations and aids around the home. As time passed many people had very little contact with healthcare services.

The voluntary sector (in this study the local MS society) seemed to fill some of the gaps left by other services. People in the study felt the individuals working for the MS society knew them personally and that they were easy to contact. This seemed to provide a sense of continuity and personal support that was lacking in other services. Others commented that they found the MS society also provided useful services such as hydrotherapy, information about MS, advocacy with other services and in some cases financial assistance. Some people were very active in the society and saw this a significant part of their lives helping others and through self help. However the MS society was not the answer for everyone. Some people felt that they did not want to

be active members of the society. (Note: recommendations for future service provision will be made in the full report that will be available at a later date)

Conclusions.

This report summarises the initial analysis of the interviews. The analysis is still at an early stage and revisions are expected to be made to it. However, it does provide some insight into the process of adjusting to MS. It suggests that adjustment to MS is a complex and continuous process. Adjustment to MS involves adjustment to symptoms, to diagnosis, to gradual changes, to sudden changes, sometimes to physical disability and in some cases requires very little adjustment. People with MS work hard to understand what the disease means and how it will affect them personally. Many individuals develop a fighting spirit in order to prevent MS taking over their lives. At the same time many people reach a form of acceptance of the situations that MS entails and that they need to plan their life around it. The study has shown how adjustment takes place within families and within social interaction. Also that many people adjust through comparison to a worse scenario image of MS. In terms of services there is a development over time away from a medical approach to a more social and self help approach. The MS society seems the main organisation providing continuous service. It is hoped that this account can be developed and will provide a basis for guidelines for future service provision.

Jonathan Reed

Psychologist in Clinical Training

APPENDIX 14

Letter to participants re respondent validation

Address

Dear

Thank you for taking part in the recent interview with me where we talked about your experiences with MS. I have now completed the first stage of the analysis of the interviews and enclose a summary report for your interest. I would really like to hear your views on this report and any comments that you make will help me evaluate the research. I enclose a feedback form for your views and a return envelope to return the form. I would be very grateful if you could return the form in the next two weeks so that I can include your comments in my final write-up. If it is difficult for you to write any comments or to post the form back I fully understand and please do not feel that you have to reply. If you have any queries or if you would prefer to speak to me on the phone please phone me on . The final write up will be much larger than this initial report and I will send you a full summary when it is completed later this year.

I have not included quotes from the interview in this report but I would like to do so in the final report. Any quotes that I do use will be anonymous and every attempt will be made to disguise them so that no one should be able to recognise who the quote is from. Please let me know on the form if you do not want me to use quotes from our interview.

Thank you very much again for your help with this research

Best wishes

Jonathan Reed

Psychologist in Clinical Training

Feedback form

Int no:

1 Feedback. Could you please comment on the content of the summary report. In particular do you agree or disagree with the analysis?

2 Do you have and further thoughts or opinions about the research, particularly your experience of the interview.

3 Are you happy for quotes (which will be disguised) from the interview to be included in the final report?

APPENDIX 15

Participant feedback on the emerging analysis

Could you please comment on the content of the summary report. In particular do you agree or disagree with the analysis?

1 I felt that the analysis was very thorough. It certainly put across the attitude of the health service in as far as once you are diagnosed you are left to cope on your own with no further clinical advice or much help with symptoms. The analysis also emphasised how most sufferers are determined to lead as normal a life as possible with what can be distressing symptoms as the MS progresses.

2. Seems adequate. I think if one could communicate on a 'one to one' basis it would be better for the patient. Seems a number of different people are involved and sometimes the patient (me) feels very isolated, maybe this is because I live on my own.

4 I agree with the analysis.

5 I found the content of the summary good, realistic and in plain English.

7. (Note This feedback was received by phone because the participant no longer had the use of his arms) I agree entirely with the analysis.

8 I do agree with the report on how it affects people in different ways. Most significant was the way the NHS are not too forthcoming with any help.

10. I was very pleased to receive a copy of your report and enjoyed reading it. It is an excellent report and covers almost all there is to understand or know about MS. All the different effects it has on different people and on their families when it is diagnosed. I agree completely with the analysis.

11. Yes I do agree with the analysis. I believe more should be done for people with MS and their carers. They have to put up with us when we get depressed. It is harder for the carer than for the person with MS.

13. I think you have covered everything very well. I don't think I can add anything else to what you have written.

14 I do agree with your analysis on MS, and I think it appears to be a very accurate report on the way that MS affects people. I hope more research will result, as it is such a crippling condition which the NHS seems to overlook. If it only brings about a better attitude in the way people are told, that will be something.

Do you have any further thoughts or opinions about the research, particularly your experience of the interview?

1 Putting one's feelings about MS into words was helpful. At no other time is one able to discuss one's personal feelings about it. Major adjustments are necessary as the illness progresses and talking to another sufferer or someone else who understands is helpful.

2. I felt the interview was conducted in a very understanding manner. Still unsure what is available for an MS sufferer which may help to ease the discomfort and pain.

4 Possibly more mention could be made of fatigue being a constant and on-going factor.

5 I thought you could have put about there not being much social life for the MS people.

8. It helped to talk to someone different about the problems of MS. The research can only do good as someone is interested in the mental approach to the fight to find a cure.

10. I enjoyed the interview and hope it was of some help to you.

11. The interview went really well, but most people with MS keep a lot to themselves and they will not talk about the problem too deeply. So therefore a written questionnaire would give more information to yourself, as the person who is filling in the form will write more about it because they do not have to face anybody.

13. I can't add anything. I think you thought of everything.

14. Any research in whatever form, is welcome, as people unfortunate enough to contract MS appear to be very much the poor relation of the NHS. It seems our partners are the ones left with the whole burden of caring for us, with little hope of things getting better as they are.

I think the interview was well done and hope it will do some good.

APPENDIX 16

Feedback from the clinical psychologist working in the field

In general I think you have produced a model applicable to the majority of MS patients (Relapse - Remitting type). There are a number of ways of cutting the cake of psychosocial adjustment: on systemic levels, neuro-psychological function, cognition's, emotions, identity, social role, health threat- coping strategies for stress and social situations. I like the way you have done it, leaving space for a sequential process over time. Also you include the adjustment to a new future: the need to create a new image of the future; even to face death.

I was struck by the lack of emotion in your sample. Maybe that is a feature of normal adjustment. Maybe it is a feature of a feature of your sample.

I think you have succeeded in describing adjustment as a normal process (like bereavement). The absence of pathology does not mean it does not need addressing by healthcare professionals. Like in the bereavement literature there may be no need to define abnormal or pathological adjustment, as it is a reflection of premorbid psychological or personality difficulties. Your theme approach sticks to the normality of reactions to MS. It also fits with other descriptions of adjustment (Strobe) which requires oscillation between 'working through' and problems solving' to get a good outcome.

Specific comments.

Theme 2 (Active adjustment)
Is particularly good.

Theme 3 (Acceptance)
Acceptance is an on going process (for professionals)
Acceptance is resignation (for people with MS)

Theme 4 (communication in families)
I was struck by how difficult your sample found this. Possibly reflects something in our society in general.

Theme 5 (Worse case scenario)
Is a gem. To keep buoyant and to define a point for euthanasia (and to give a sense of control).

APPENDIX 17

Feedback from the welfare secretary at the MS society.

Having read your report, I agree completely with the analysis. Living for 20 years as a carer to my late husband, I can relate closely to so much of your report, especially (b) adjustment to diagnosis. So many time have I known- and this is my own experience- of the neurologist telling the relative but, advising against telling the patient. This can/ does cause friction in relationships quite unnecessarily.

APPENDIX 18

Biographical sketches showing participant characteristics *

Keith aged 59 had been diagnosed with MS fifteen years ago. He first noticed something was wrong when he went blind in one eye. He had very few symptoms for the first twelve years after diagnosis. However, since taking early retirement three years prior to the interview, he had deteriorated significantly and was finding it difficult to get out on his own even with the use of a walking stick. Keith had worked as a civil servant for most of his life and had worked his way up to a senior management level. He lived on his own after his marriage had broke up and had two grown up children living away from home.

Ian aged 60 was diagnosed with MS 10 years ago. He was single and had worked most of his life in the licence trade. His MS developed through periods of relapse and remission and he had gradually deteriorated in terms of mobility and strength. He had had to retire early because of his MS three years prior to the interview. Ian was able to get out providing he had a walking stick.

John aged 64 had been diagnosed with MS for twenty years. Initially he had not been told his diagnosis and only found out four years later when his GP sent off for his old medical notes. John had originally been in the army and had later worked in a variety

* All names and identifying information has been disguised.

of manual jobs in manufacturing. He was married with two grown up children. His MS had developed through periods of relapses and remissions and he had become gradually more disabled over time. At the time of the interview his main symptoms were fatigue and difficulty when walking which, much to his reluctance, required the use of walking sticks.

Kathy aged 43 had been diagnosed with MS for seven years. Her MS also developed through periods of relapse and remission, however she had suffered eight relapses in the first year after diagnosis. This led to her having to use a wheelchair fairly quickly and she became incontinent. After a few years she tried an alternative treatment and her relapses slowed down and she started to walk again. At the time of the interview she still needed to be in a wheelchair when going out but could walk around with a stick indoors. She was married with two small children and before she was diagnosis she had worked as a secretary.

Susan aged 55 was diagnosed with MS 12 years ago. She had two grown up children and was divorced. Her MS had progressed steadily and by the time of interview she was significantly disabled. She used an electric wheelchair and had weakness in her arms. She lived on own and had carers provided by social services visit three times a day. Prior to the diagnosis she had worked as a school matron and secretary.

Peter aged 58 had been diagnosed for ten years. He was married with a grown up step daughter. His MS progressed through periods of relapse and remission and he had

gradually become more disabled. His main symptoms were lack of mobility which meant he was permanently in a wheelchair. He also had tremors which affected his arms and made fine motor tasks difficult. This was especially difficult for him as he had worked in the building trade all his life and had been a skilled craftsman.

Irene aged 66 had been diagnosed with MS for twenty years. Her MS had progressed gradually but steadily without relapse. She was unable to walk and used a wheelchair when going out. She was married with no children and relied on her husband to do tasks around the house and to help her. She had previously worked in a factory on a production line but when she was made redundant shortly after diagnosis she did not look for another job because of her MS.

Vera aged 78 was diagnosed with MS 45 years ago. She had not been told that she had MS until 10 years after the original diagnosis. After an initial attack she had only had two other attacks in 45 years. For much of the time the MS had not intruded into her life. She had worked in a variety of jobs including school secretary, administrator and receptionist. Her husband had died three years prior to the interview and she had two grown up daughters one of whom also had MS. At the time of interview she was using a walking stick to get around and still drove her car regularly.

Charles aged 55 was diagnosed with MS 10 years ago. He had two grown up children and had recently separated from his wife. His MS had progressed through periods of relapse and remission. At the time of interview he needed a walking stick

around the house and for going out. He used to work as accountant but had to leave the job as his MS became worse.

Pam aged 51 was diagnosed with MS 15 years ago. Her diagnosis had been difficult and she had eventually had to go to a specialist hospital in London to confirm it. She had done a variety of jobs in the catering industry but had had to give up work shortly after her diagnosis. Her MS had developed through cycles of relapse and remission and she had become more disabled and was now permanently in a wheelchair. After the diagnosis she had suffered severe mental health problems and had to be admitted to hospital. She believed this was mainly a reaction to the disease and had felt better for several years since then.

Barbara aged 63 was diagnosed 12 years ago. She used to be a manager but had had to give up work because of her MS. Her MS had progressed through a pattern of relapse and remission and she had gradually become less mobile. She used a stick but had fallen over frequently and on one occasion had broken her leg badly. At the time of interview she used a wheelchair when going out. She was married and had one grown up son.